"I feel so safe here." An exhibition of stories: collecting and sharing oral histories of St Helena Hospice, north east Essex
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Date of submission for examination September 2025

## **Abstract**

St Helena Hospice stories collection: Heritage and Life Stories exhibition was a public exhibition telling the story of the origin of hospice care in north east Essex through oral history and celebrating the lives of its patients 40 years on. Oral history recordings matter to the people who told their story, whether because they are reflecting on their contribution to St Helena Hospice, or because they are receiving palliative or end of life care from it. The result was a collective experience for the interviewees, the researcher, and the visitors who listened to and read the stories.

This Practice as Research project is followed by a Dissertation exploring how the hospice movement came about in post-war Britain, bringing with it a change in the language and visibility of dying and death, and a change in the care of people with incurable illness. St Helena Hospice was one of the hospices established in the mid-1980s as a result of these developments, as shown through firsthand stories collected and presented in the exhibition. It also looks at the connection of journalism in oral history, and oral history in a palliative care setting, and together their use in creating an audiovisual exhibition.

## **Acknowledgements**

With sincere thanks to Dr Elizabeth Hall and the people who gave their time for an oral history interview about the origin of St Helena Hospice.

With heartfelt thanks to the people who gave their time to share their memories and thoughts near the end of their lives: Arthur, Beryl, Catherine, Daisy, Ernest, Jacqueline, Julie, Kit, Malcolm, Mark, Neil, Rod, Ron, Rosie and Viv.

And thank you and best wishes to the families for allowing the continued use of their loved one's voice and image.

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## **Practice as Research outputs**

The **St Helena Hospice stories collection: Heritage and Life Stories exhibition** forms half of the Masters by Dissertation Practice as Research submission.

A **public exhibition** held at three venues with accompanying booklets and digital collection, evidenced by:

- Video of the exhibition held at Firstsite, Colchester; Martello Tower, Jaywick;
   and St Helena Hospice
  - https://youtu.be/7wPvCNLueLI

#### 2. Photos of the exhibitions

Appendix B

### 3. Accompanying booklets

- Appendix C Heritage Collection
- Appendix D Life Stories Collection

### 4. Artwork panels

- Appendix E Heritage
- Appendix F Life Stories

### 5. Digital collections

- www.sthelena.org.uk/heritage
- www.sthelena.org.uk/lifestories

### **Documentation of Creation**

This Documentation of Creation follows the steps in chronological order to producing the *St Helena Hospice stories collection: Heritage and Life Stories exhibition* audiovisual public exhibition telling the story of the origin of Hospice care in north east Essex through oral history and celebrating the lives of its patients 40 years on.

The projects named within this document which combined became 2025 final exhibition, are referred to as Heritage (origin of the Hospice) and Life Stories (present patients). This document outlines the project and decisions made, while the accompanying Reflective Report discusses my thoughts and reflections on the two complementary areas of focus and the overall project as a whole.

In summer 2018 I registered as an MA by Dissertation (MAD) student at the University of Essex, later Practice as Research (PaR), proposing to research the origin of St Helena Hospice by telling the story of the charity through oral histories of people who set up the organisation, people involved in its early years, and people who benefit from its work today. By spring 2019, I had secured external funding of £73,000 from the National Lottery Heritage Fund (NLHF) so I could upscale my oral history project and work on it as part of my storytelling role at the Hospice working on the *St Helena Hospice Heritage Stories* project. I achieved further funding of £14,000 from Essex County Council (ECC) Arts & Cultural Fund in 2024 to support the recording of memories of patients in the *St Helena Hospice Life Stories* project. Both projects were presented as one public exhibition of past and present celebrating the charity's 40<sup>th</sup> anniversary in 2025, *St Helena Hospice stories collection: Life Stories and Heritage exhibition*. I was responsible for creating all outputs and curating the exhibition, and I mention in this document where I used the

external funding to engage a professional designer and printer who worked to my brief to produce the exhibition artwork.

During the project, I attended several courses accredited by Oral History Society (OHS) and National Life Stories at the British Library: Digital Editing; Recording oral history interviews on video; Oral History in Palliative Care; Archival Management of Oral History Collections.

## **Heritage**

#### Ethical approval and informed consent

The first step was to prepare an information sheet and consent form (Appendix A) and submitting these along with the University of Essex *Application for Ethical Approval of Research Involving Human Participants*, which were approved and sent to central deposit in June 2018. Recording and presenting patient stories for marketing purposes in my Hospice role has a granular consent process and statement about how personal data is held, and I additionally sought approval from the St Helena Hospice Ethics Committee, which was granted in July 2018. A revised information sheet and Life Stories Recording Agreement and consent form was created in 2024, with support from the Hospice's Head of Quality and Compliance, for patient participants to sign and acknowledge that parts of the recording would be used in a public exhibition, with additional options to consent to words, audiovisual and photographs to be shared by Essex County Council Arts & Culture Fund, and a

<sup>&</sup>lt;sup>1</sup> Oral History Society and National Life Stories at the British Library, *Training Accredited* (n.d.) <a href="https://www.ohs.org.uk/">https://www.ohs.org.uk/</a>>.

further additional option added with support from a Sound Archivist at Essex Record

Office for the interview to be archived at the Essex Sound and Video Archive.

### **Hospice archive**

The Hospice library was in the process of downsizing and the librarian, knowing my interest in the history of the charity, made me custodian of the numerous archive boxes of unsorted photos, mixed documents, newspaper clippings, newsletters and annual reports. Over a few months, I sorted them into categories and dates and began to create a timeline, and familiarise myself with names of people and their roles in the origin of the Hospice.

A box of VHS tapes was among the items which came from the Hospice library with handwritten titles such as *Queen Mother* and *The Early Years*. I commissioned a local business to convert them to a digital format and this uncovered film footage including the construction site of the Hospice building from 1984; film of the nursing team outside the Hospice during the week before opening in 1985; footage of local news coverage of the first six months; and videos made by Colchester Camera Club of Royal visits to the Hospice in 1986 and 1988.

I called upon my contacts at the local Daily Gazette newspaper for access to their archives and spent a few hours in the newsroom going through physical folders of clippings about St Helena Hospice from 1979 to 1986.

#### Finding and recording Heritage participants

I researched audio recording equipment, taking into account advice from the Oral History Society, and chose a broadcast quality Zoom H2N audio recorder for capturing the oral histories, along with an external hard drive for backing up the files.

I won a £500 grant from the University's Phillip Hills Award which helped fund a camera so I could photograph each participant.

People who had been involved with initial discussions about the Hospice in 1979 and the early years of its operation were aging, and I soon learnt some had died, so there was a limited window to capture the remaining stories to preserve the memories of St Helena Hospice's Heritage. I was already in contact with one of the principal founders, Dr Elizabeth Hall, and I compiled a list of names of original staff and volunteers based on her contacts and memories. The charity's fundraising database had a few details of 'friends of the Hospice'; people who had been paying a £1 a year membership since the early 1980s to help with the fundraising appeal to build the Hospice. Some of the people who had volunteered on the steering committee to drive the appeal forward were located and willing to be interviewed about their role in setting up the Hospice, including a former Colchester Mayor who 'discovered' what would become the Hospice inpatient building, along with the volunteer who took care of public and media relations promoting the appeal.

The interviews at first were people who had been on the appeal steering group but once news of the project spread among staff and volunteers and I began using the Hospice's communications platforms, the pool of storytellers widened and people with a range of roles in the set up and early years were found. The inpatient unit matron at the time mentioned she had been a newly qualified staff nurse when the Hospice opened in 1985, going on to record her memories of that first day, which later became a podcast,<sup>2</sup> and putting me in contact with another nurse who started at the same time. Records from the Hospice voluntary service team identified four long

<sup>&</sup>lt;sup>2</sup> St Helena Hospice Heritage Stories, with guest Sue O'Neill (n.d.) <a href="https://soundcloud.com/sthelenahospice/st-helena-hospice-stories-podcast-episode-1">https://soundcloud.com/sthelenahospice/st-helena-hospice-stories-podcast-episode-1</a>.

serving volunteers; two gardeners who had helped to transform the land around the Hospice building, and two ward and kitchen helpers who had started during opening week. A chance conversation led to an introduction to a lively group of friends who had been fundraising since the appeal was launched in 1980, and of the four remaining members three were recorded on video for the project.

One volunteer receptionist mentioned she was a friend of the father of the Hospice's first patient, 22 year old Lisa Brenchley. I invited Lisa's father and sister to record their memories of Lisa's time as a patient, drawing on my interviewing experience as a practitioner in storytelling at the Hospice with bereaved people recollecting emotional experiences. Several former clinical staff during their interviews recalled Lisa and her family by name unprompted, such was the impact on them.

Further interviewees were found through responses to articles in the Hospice supporter magazine and email newsletters, and many came from the charity's official social media channels after I posted a retro photo of the original nurses. One comment, and subsequent interviewee, came from a retired builder who said he had worked on the conversion of the original farmhouse into the inpatient unit in 1984. By the time the first exhibition was held, I had recorded 38 oral histories, anecdotes and memories on the development of local hospice care, with people who held a diverse range of roles including the first cook, a volunteer in the first St Helena Hospice shop, a first treasurer, and the publisher of the local newspaper group which had backed the appeal to start a Hospice in north east Essex.

After each recording session I made notes and identified timecodes of key areas spoken about by the interviewee to support the exhibition editing process further into the project.

#### Pandemic pause

The pandemic, ongoing Covid restrictions and subsequent extra infection control restrictions at the Hospice, paused work on the project and MAD PaR from summer term 2020 until mid 2021. However, I produced a week-long social media takeover publicly marking the 35<sup>th</sup> anniversary of St Helena Hospice in May 2020. I featured retro Hospice photos and written quotes and audio taken from some of the oral history interviews, and the posts became informal digital reminiscence sessions with people across the community engaging and commenting with their own memories. I also issued a press release to the Daily Gazette with excerpts of eight of the oral histories I had recorded, an origin timeline and vintage photos, resulting in five pages published on the 35th anniversary day, 20<sup>th</sup> May 2020. I provided content for a further nine articles during the ongoing pandemic restrictions for the paper's 'Nostalgia' pages.

Given the uncertainty of the pandemic, the NLHF agreed to revise the deadline for delivery of the project. With ongoing restrictions at the Hospice and pausing work on the project, plans to produce an exhibition in the Hospice's 35<sup>th</sup> anniversary year were postponed. Instead, I aimed towards October 2021 to host the Heritage exhibition during Hospice Care Week, and booked the Hospice day centre as the venue as it could be cancelled without charge if national or local restrictions changed in the autumn, and planned a digital exhibition on the Hospice website.

#### **Editing and designing Heritage**

I decided to call the exhibition *St Helena Hospice Heritage: a stories collection*. I returned to the notes and time codes I had made after each oral history recording and began selecting and editing sections using Adobe Audition and a Hospice admin

volunteer supported with transcribing those sections, making it clearer for me to select the short quotes from the transcripts which would contribute to telling the story of the origin of the Hospice. At the same time, I prepared slightly longer quotes and scanned further photos for an accompanying booklet which would tell more of the Heritage story.

A proportion of the costs budgeted for in the NLHF grant was for design and print costs for the exhibition, so I commissioned a local designer and local printer to produce the artwork to my brief. I selected appropriate photos from the Hospice archive to go with the people and quotes, using images containing the interviewee where possible, and scanned them to high resolution so they would reproduce well when enlarged. Newspaper cuttings were helpful in identifying the interviewees and identifying other people for creating photo captions for the artwork; the Hospice has a long-standing agreement with the newspaper company about reproducing its content. The majority of the photos from the archive were black and white press photos which gave them a nostalgic look and feel, fitting with my overall vision for the exhibition. In contrast to the black and white photography, I chose a soft orange pantone colour from the Hospice's branding suite for speech marks around the selected quotes, which gave a retro vibe. I briefed the designer to create an introductory panel using a selection of scanned Heritage images framed in the style of a photographer's contact sheet (Fig 1.1), a tool traditionally used to preview images from a film camera roll before developing a full size print, inspired by a contact sheet I had scanned of The Queen Mother's visit to officially open the Hospice in 1986.

I wanted the artwork to be reusable for future touring of the exhibition into communities served by the Hospice where there may not be wall space to display the artwork. I researched eco exhibition materials and decided on totems; threesided panels 2000mm x 900mm which were a substitution for an exhibition wall. I briefed the designer to place on each panel a different A2 landscape square 595x595mm black and white photo at eye-height with a quote underneath enclosed in orange speech marks. There was an expanse of white under this where I requested a semi-transparent greyed-out image representing the corresponding part of the timeline that the quote described. Four eras of the early timeline were shown that way: a plain rectangle to represent a blank canvas on which the Hospice foundations were built on; a montage of newspaper cuttings about the Hospice appeal from 1979-1984 representing the Hospice's fundraising appeal; the architect's plans representing the building work; and a section of the completed Hospice building to represent the opening and early years of its existence (Fig 1.2). Further quotes and images were designed as A1 landscape square 841x841mm and printed on FSC boards to display on artist easels. To accompany the exhibition, an A6 postcard and a 72 page A5 booklet were produced following the same design style to accompany the exhibition, printed locally on 100% recycled and recyclable paper.

While the artwork was at the printers, I refined the edited audio clips to between four and seven minutes long to use in the interactive element of the exhibition and online, then uploaded them to Soundcloud to be able to embed them on the St Helena Hospice website. Some of the grant money was used to commission the Hospice's website provider to build an interactive timeline, and I had support from a Hospice IT technician to set some digital tablets to 'kiosk mode' in order to keep interactivity in

the right area of the website so exhibition visitors could explore the Heritage timeline, listen to audio clips of the oral histories and watch clips of the digitally converted videos.

#### Heritage exhibition

In October 2021 I installed the *St Helena Hospice Heritage: a stories collection* exhibition at the Hospice day centre, putting together the printed totems, setting up the boards on easels in chronological order around the room, and adding the digital tablets encased in stands, along with a few original branded items such as Hospice charity shop bags, pin badges and early fundraising items. As the weather was mild, I opened the folding doors to the decking outside in the garden overlooking the grade II listed farmhouse side of the Hospice and placed some of the artwork on the decking, deliberately placing one which had a photo of the same view in 1981 before any construction work had taken place (Fig 1.3).

The Hospice's continued Covid restrictions limited the number of people allowed in a room, so I invited interview participants to view the exhibition in groups spread out during the week according to their involvement in the origin of the Hospice. The majority of people interviewed were over the age of 70 and, predictably, several declined to attend as Covid was still prevalent, so I posted the accompanying booklet and postcard to them. There were great photo opportunities of visitors next to the artwork featuring them (Fig 1.4).

Time in between viewings was set aside for staff, volunteers, patients and visitors to drop in. Will Quince, the Colchester MP at the time, had accepted my invitation to view but cancelled the visit last minute and instead invited me to show the exhibition at his community day at Firstsite gallery a few weeks later (Fig 1.5).

Earlier that year I had submitted an abstract to present a poster about the oral history project for the Hospice UK national conference and I was asked instead to deliver a presentation at the conference in November 2021. I used images and audio clips from the exhibition to make the presentation engaging and informative for the audience in the lecture theatre.

In December 2021 I explored options of holding the exhibition in other locations within the Hospice's north east Essex catchment area, deciding on Martello Tower on Jaywick Sands seafront which has a gallery space for community heritage and arts, and secured a six week run from March to April 2022. Jaywick Martello Tower is an ellipse shape with a cylindrical pillar inside the centre and limited floor space, so I needed to resize the printed artwork panels for wall mounting, opting for A3 landscape square 420x420mm printed on wipe-clean vinyl for infection control and reuse. I revised some of the written quotes and photos on a few panels and briefed the designer to create an end panel using the film contact strip style of the first panel and booklet cover, replacing the heritage photos with pictures of people I took at the time of interviewing. I used Command poster strips to place the panels in position in the gallery space to prevent damage to the walls of the historic building. After deinstallation of the Jaywick exhibition in April 2022 I took a break from the project and MAD PaR, other than producing a few Heritage posts on the St Helena social media platforms using written quotes, audio and video clips yearly on the anniversary of the opening and Royal visits.

### **Life Stories**

## Finding and recording Life Stories

Two years later in May 2024, I began work on the *St Helena Hospice Life Stories* project after achieving a £14,000 grant from ECC Arts & Cultural Fund, partially funding my role, to capture life stories and memories of St Helena Hospice patients. I planned for the new Life Stories project to be a continuation of the Heritage exhibition to mark the Hospice's 40th anniversary the following year.

I produced an A6 size postcard outlining the Life Stories project offering to patients a chance to record their memories and receive a USB memory stick as a legacy to do with as they wish, and with their consent, to feature a small section in the Hospice exhibition. Postcards were given to Hospice community nurses and rehab team for their patients cared for at home and postcards were displayed in the inpatient unit.

During the project, 15 people agreed to be featured in the exhibition and I recorded them in the location where they were receiving palliative care, at home or in the inpatient unit, and I photographed each participant. I roughly edited potential clips for the exhibition shortly after each session, avoiding sections they intended only for their loved ones.

#### **Editing and designing Life Stories**

I visualised the exhibition artwork to show each person as they were when they spoke about and reflected on a life lived. At the time of recording, I had photographed them each in the same portrait style but I had considered asking the participant to submit a photo themselves but ruled that out as an option as they had varying capabilities of finding, scanning or sending a photo of themselves, either

through technical ability or no access to equipment. There was also the possibility the image would not be high resolution quality to enlarge for printing large scale. By taking the photo myself, I could include a hint of the background surrounding them to increase the narrative as some were interviewed in their home and others in the Hospice inpatient unit. The background was important as it could subtly show the economically diverse catchment area of the Hospice, raising awareness that people from wealth and poverty are supported by St Helena Hospice, or to illustrate they were clearly confined to one space as their health deteriorated. Nine of the 15 interviewees agreed to also be filmed answering a few set questions which I intended to edit together as a visual to show at the exhibition.

I felt it was important to keep the written quotes verbatim and with dialect to keep them authentic, not sanitising the grammar. I planned for Life Stories to complement the Heritage stories, therefore I followed the same visual of a large photo with accompanying quote surrounded by large speech marks. As I had already identified and clipped the short sections of audio to be included, I quickly transcribed and selected quotes I thought would be impactful to accompany their photograph. The ECC funding meant I could hire the local designer again with a brief to recreate the new artwork to match the Heritage artwork, however, this time the photos would be in colour to give a feeling of the present in contrast to the black and white past. At the same time, I prepared slightly longer quotes to produce an accompanying booklet in the same style as the Heritage booklet.

I maintained stewardship of the interviewees throughout; of the 15 patients who recorded their oral history, 11 had died by this stage and I sent the relevant artwork

to their loved ones for approval, with the remaining four patients having approval of their own artwork.

As the themes of Life Stories and Heritage were to be combined into one exhibition celebrating past and present of the Hospice, I needed a big space to make a big impact. I negotiated two large gallery spaces at Firstsite in Colchester to hold the exhibition on the actual 40<sup>th</sup> anniversary day of the Hospice opening, 20<sup>th</sup> May, and the following day. With the high-profile public venue secured, I additionally booked space at the Hospice's day centre overlooking the pond and Hospice building as previously used so staff, volunteers, patients and visitors could engage in the celebrations too for two days at the end of the anniversary week. I also thought the accessibility and parking on site would suit some of the invited guests with mobility issues. Although it is a smaller space, some of the artwork could be moved there after the showing at Firstsite. Both venues are ground floor, accessible and open for the public to view free of charge. Jaywick Martello Tower had been a welcoming community space within the Hospice catchment area previously and I was confident about the space and visitor numbers, so booked for a six week run at the gallery May to June 2025, incorporating the anniversary day. The venue charged £1 entry for adults towards the upkeep of the Tower and the gallery space is upstairs with one chair lift available. The venues would appeal to different audiences and were strategically geographically placed within catchment area. I chose the same three venues as I had exhibited the original exhibition at as I was familiar with the set up and space, and importantly, I wanted a second go to improve the experience and engagement marred by Covid restrictions.

The showing at Jaywick Martello Tower was set to open on 1<sup>st</sup> May a few weeks before Firstsite and needed the artwork produced differently according to the space and quirky shape of the venue as previously described. I had the photo and quote artwork panels designed and printed on wipe-clean vinyl to match the style of the original 420x420mm Heritage pieces. I installed the colour printed Life Stories around the centre column of the gallery and in the window recesses which looked out at the coast – particularly poignant where I knew the storyteller loved the sea – in alphabetical order by first name. I placed the black and white Heritage prints on the surrounding curved walls (Fig 1.6).

The three sided Heritage totems printed as gallery walls for the original Heritage exhibition were not as portable or reusable as I had anticipated and I had to cut them during deinstallation in 2021, so using the remaining restricted funds from the NLHF, I had new totems printed slightly narrower at 700x2000mm for easier transportation, and this time with Velcro fastenings to hold each piece in place. As they were being reprinted, I took the opportunity to revise some of the Heritage quotes and photos. I briefed the designer to continue this style to create new totems for the Life Stories section, with the portrait photos in colour to show the present, and under the main image and quote to use semi-transparent greyed-out Polaroid-style photos of the portraits in the style complementing the four eras of the timeline on the Heritage panels(Fig 1.7). I commissioned 5x 3-sided Life Stories totems with a panel for each of the 15 patients and planned to set up these along with eight Heritage totems at the Hospice for the second half of anniversary week. As the Inner Mosaic room at Firstsite, where I had planned to host the Life Stories section, has wall space on three sides, I took the opportunity to have nine of the panels printed each on A2

landscape square 595x595mm vinyl to attach to the wall of the room and to use two of the Life Stories totems in the middle of the room.

The Life Stories audio clips were edited to between five and seven minutes and uploaded to Soundcloud so I could create a page for each story on the Hospice website, with the transcript and link to the audio file. Building the Life Stories section of the St Helena website brought a few frustrations as I had to recall how to do certain technical tasks in the back end. Once the pages were ready, I created QR codes to link to each patient's page for visitors to scan and listen to the person's voice and printed them Polaroid-style from an instamatic camera to tie in the Polaroid-style greyed-out images on the panels of the totem artwork. Digital tablets were set to kiosk mode by the Hospice IT technician again ready to show the Heritage and Life Stories sections of the website for exhibition visitors to explore.

I watched back the videos I had recorded of nine patients answering set questions and I chose the two questions which had the most varied answers: What was your favourite age or decade? What makes you happy? Using Adobe Premiere Pro, I edited together the responses to the two questions and uploaded to the Hospice's YouTube channel, created another page in the Life Stories section of the website and embedded the YouTube videos. I also edited a new Heritage video from the digitised VHS tapes. Firstsite had televisions available in both rooms and I could play the videos on a loop in the respective rooms at the exhibition.

## The 40th anniversary exhibition 2025

With the printed artwork, booklets and postcards back from the printer and the audio, video and website published, I was ready to show *St Helena Hospice stories collection: Life Stories and Heritage exhibition*. Invitations to two private viewing times, along with the dates open to the public as an alternative, had been sent out to participants and their families. I invited the Heritage interviewees (a few had died since their recording) and other people involved in the early days of the organisation, to a private viewing on the afternoon of the 40<sup>th</sup> anniversary. I had arranged for Dr Elizabeth Hall, one of the principal founders and my first interviewee who had inspired the project, to give a welcome speech. The bereaved families and friends of the Life Stories participants and the four living patients and their loved ones, were invited to view the exhibition at any of the three locations with an open invitation to either of the private viewings.

To publicise the exhibition, I was interviewed on Colne Radio and created posts for St Helena Hospice social media platforms. I spoke to my contacts at the local Daily Gazette newspaper and wrote a press release about the 40<sup>th</sup> anniversary, providing them with long quotes taken from the Heritage oral histories, with re-consent from interviewees, and sent a selection of vintage photos, which resulted in four pages in the newspaper on the 40<sup>th</sup> anniversary day, including details of the exhibition dates and venues.

I installed the exhibition at Firstsite on the opening morning with the support of my husband, transporting the artwork to the venue, building the totems, measuring the spacing in between the wall mounted panels and securing and levelling them. I placed the Polaroid-style QR codes next to each Life Story so visitors could scan

them and listen to the audio clip, and I set out the accompanying booklets and postcards for visitors to take. I set up the audio-visual elements; a tablet on a stand in both rooms for visitors to interact with to read or hear the clips, and I set USB memory sticks with the two videos to play on the televisions on auto-repeat. Life Stories was installed in the Inner Mosaic space along the main concourse of the gallery so visitors would see it through the glass wall and could be drawn into the space, and the Heritage section was installed in the adjoining large studio.

Two hours (and a parking ticket) later, both exhibition rooms were ready in time for the gallery's public opening. There was a steady stream of visitors over both days in between the one-hour private viewings on both days, with the session on the actual anniversary becoming an informal reminiscence session for visitors (Fig 1.8).

The deinstallation from Firstsite was fairly quick between the two of us and early the next morning we installed 13 totems, tablet stands, booklets and postcards in the day centre at the Hospice. Deinstallation took place the following afternoon and the artwork pieces taken to the Hospice's storage area.

Since the anniversary week exhibitions, selected artwork has been displayed at a several Hospice supporter events, with further requests received from colleagues to use on upcoming future occasions.

#### Illustrations

FIG 1.1.



Introductory panel using a selection of scanned Heritage images framed in the style of a photographer's contact sheet.

FIG 1.2.



Example of artwork totem showing an era of the timeline below the main picture, in this case a montage of newspaper cuttings about the Hospice appeal from 1979-1984 representing the Hospice's fundraising appeal.

FIG 1.3.



Artwork in the same view of the Hospice in 1981 before construction work took place.

FIG 1.4.



Cherrydale Weavers in October 2021 next to exhibition artwork featuring them in a newspaper cutting in 1981.

FIG 1.5.



Will Quince, the Colchester MP at the time, viewing Heritage artwork in Firstsite gallery, November 2021.

FIG 1.6.



Life Stories artwork in colour around the centre column of Jaywick Martello Tower gallery and in the window recesses which looked out at the coast, and black and white Heritage artwork on the surrounding curved walls, May 2025.

FIG 1.7.



Example of Life Stories totem artwork in colour with semi-transparent greyed-out Polaroid-style photos below.

FIG 1.8.



Private viewings on the 40th anniversary day, 20<sup>th</sup> May 2025, with guests including original members of staff and Heritage interviewees.

## **Reflective Report**

This is a Reflective Report on creating *St Helena Hospice stories collection:*Life Stories and Heritage exhibition, an audiovisual public exhibition telling the story of the origin of Hospice care in north east Essex through oral history and celebrating the lives of its patients 40 years on.

Hospice care is life-changing for patients and their loved ones. As a practitioner in working with patient and family stories at St Helena Hospice, I see the positive impact of hospice care and have the job of retelling their experiences for a mass audience in my role as Media and Stories Lead in the Marketing and Communications team. I have been an employee with the organisation since 2013 and for the majority of that time have been focussed on sensitively gathering and creatively presenting stories of people involved with the charity – people supported as a patient and the people important to them (described as family), and the people delivering its services as staff or volunteers. I have shaped the role to use appropriate writing, audio, video and photography to share lived experiences to raise awareness of hospice care, having built relationships with staff and volunteers and then stewardship of patients and families. My first degree back in 1994 was in journalism and I've worked in press and PR since, much of it in the third sector which has revolved around communicating real life stories ethically and accessibly. At times, there can be an emotional tension for me when I spot what I think would make a good journalistic story but given the sensitivities of the person's situation or feelings, particularly at the hospice, have chosen not to pursue it or have approached it more sensitively, expecting rejection. My experience with patient and family life in a palliative care setting, coupled with my creative role at St Helena

Hospice and background in press and media, made the idea of combining these interests to produce an exhibition of hospice stories, compelling.

While filming a brief history of St Helena Hospice for a staff induction video with one of its principal founders, Dr Elizabeth Hall, I realised there wasn't much accessible information about the origin of the Hospice nor a comprehensive timeline. Off camera Dr Hall had joked about some of the things that happened at the beginning, which prompted me to wonder about the personal stories of the people who were involved. What went on behind the scenes? How did the community feel about the prospect of local hospice? What did the people who set up the Hospice feel about their achievement? I had previously completed an Introduction to Oral History course,<sup>3</sup> inspiring my interest in using the methodology of oral history to bring the Hospice's history to life. The charity's 35<sup>th</sup> anniversary was coming up in 2020 presenting an opportunity to share its origin story with staff, volunteers and the wider community in celebration, and to preserve the heritage of the hospice by capturing oral histories and memories. I set out to present this as a public audio-visual exhibition covering the period from the first public meeting in 1979 and up to the first three years of operation in 1988, when the concept of local hospice care was new and clinical staff were finding their way in the new arm of palliative care.

As a practitioner in storytelling in a palliative care setting, asking people to recollect emotional experiences is at the core of my role, and I'm comfortable with spotting a story, interviewing, listening, guiding people through their own thoughts, and then sensitively editing the written piece and audio and video recordings, creatively pulling key passages to tell a story. So, I was confident that oral history would be an

<sup>&</sup>lt;sup>3</sup> Oral History Society and National Life Stories at the British Library, *Training Accredited*.

interesting and powerful methodology to deliver an account of the origin of the Hospice, together with an empathetic vignette of people at the end of life.

Not long into the project, I could see there was a great deal more to be covered than I first thought and it needed to be done well in honour of the founders, and done soon, as the people involved were aging and there was a danger of memories and stories being lost. I researched funding opportunities, wrote a proposal for the recording and preserving of oral histories of the hospice and sharing through public exhibition, securing £73,000 from the National Lottery Heritage Fund (NLHF) so I could upscale and incorporate the oral history project into my hospice storytelling role.

Half way through the project, the pandemic happened yet I managed to produce a small Heritage exhibition late 2021 and early 2022, and decided that would be seen as a trial run for a bigger and better public exhibition in 2025 to celebrate 40 years of St Helena Hospice. The extra time meant I could apply for further funding to support the recording of patients' life stories in a project recognising life before diagnosis, securing £14,000 from Essex County Council (ECC) Arts & Cultural Fund.

This report reflects on the two projects which combined became the 40<sup>th</sup> anniversary *St Helena Hospice stories collection: Life Stories and Heritage exhibition* in 2025 – origin of the Hospice (Heritage), present patients (Life Stories) – and the overall final exhibition.

## Heritage

Why do this project, now? Nobody else was doing it. The number of the surviving founders of St Helena Hospice was dwindling and other people involved were getting older, so there was a risk of losing precious first-hand accounts. Facts and figures existed but these memories are part of its heritage and the soul of the organisation, regardless of what it has become 40 years later or where it's going in a financially challenging landscape. There were some, but few, staff and volunteers with more than 30 years' service who could recollect the early days, and new joiners accepted that the organisation existed but weren't asking how or why it came about. While the hospice sector changes and develops and progresses, it started somewhere, and without the story being told by the people who were there, the richness of the organisational history would be lost, and that mattered to me as a storyteller.

However, the project became bigger, more time-consuming, and had more interest from my workplace than I had anticipated. Nothing like this had been done on this scale before; Colchester Recalled had a few recorded interviews archived and there had been some newspaper articles published on previous anniversary milestones.

During the Heritage project, the local Daily Gazette newspaper gave me access to its archives and I spent a few hours in the newsroom going through many ring binder files of clippings about St Helena Hospice from 1979 to 1986. They had been stuck to paper with sticky tape, now yellowing and tatty, which for me, symbolised a further need to do this project before memories faded and were forgotten.

Given my journalistic background, interviews lasted no more than two hours and were unstructured other than I wanted them to tell me who they are, what did they

do, when did they do it, and why they did it, starting with a direct open-ended question along the lines of 'tell me about your involvement', as I wanted an authentic account and to see where the conversation went. The "related but separate" connection between journalism and oral history<sup>4</sup> is discussed in chapter 2.

Recordings were made either in the interviewee's home or at the Hospice, depending on their preference and health. People who visited the Hospice were able to look around and reminisce about their role in getting it off the ground, the friends they made along the way, and they could picture where some of the events they spoke about happened. The location gave a better emotional response and led to branching off into more personal stories about the early days. Some interviews were recorded in people's homes and were enhanced with browsing through a scrapbook of news cuttings and photographs. The interviews were more structured recollections compared to my usual experience with people connected to the Hospice; most were guarded when speaking about patients they remembered, keeping up their professional standards by keeping names confidential, and few gave away feelings other than joy at reminiscing, a contrast to hospice staff now who opening share emotions.

One interviewee was cautious in naming people involved for fear of leaving someone out, while another was dismissive of a participant's claim on the extent of their involvement but with oral history, people remember things differently<sup>5</sup> adding to the rich narrative. One key player in the origin story was missed because several participants had told me she had died years ago. It wasn't until a letter printed in the

<sup>&</sup>lt;sup>4</sup> Mark Feldstein, 'Kissing Cousins: Journalism and Oral History', *The Oral History Review*, 31.1 (2004), pp. 1–22.

<sup>&</sup>lt;sup>5</sup> Alistair Thomson, 'Making the Most of Memories: The Empirical and Subjective Value of Oral History', *Transactions of the Royal Historical Society*, 9 (1999), pp. 291–301, doi:10.2307/3679406.

local newspaper about her after she died, that I found I had missed the opportunity by just a few months which I felt was shame as given her role, would have made an interesting contribution, but instead I recorded the author of the letter about his memories of her involvement, along with the part he played, which meant I had preserved her name in the project.

Reminiscence sessions with members of the community may have produced interesting stories but unfortunately did not go ahead in person with continued Covid restrictions. Instead, I used the hospice Facebook account to provoke reminiscence by featuring photos found in the archives, along with quotes taken from oral histories I had already recorded, and those digital reminiscence sessions with the community widened the pool of stories to follow up. After posting a video from 1988 of Diana, Princess of Wales, opening the hospice day centre, three unconnected people made contact to ask if there were any photos of their relatives who had been there on that day. After digging for images matching their descriptions, I found there were photos of their loved ones along with some video clips that the families didn't know about, and these precious images and footage were sent to them. This unexpected interaction was a lovely moment for me, knowing the work I was doing was bringing something valuable to someone's life.

Along the project's way, I became the go-to person to provide detail about the history, quotes and photos when people require information and content for fundraising activities. Working in the hospice marketing team, I know how valuable stories of real people are in helping to raise funds in an organisation which relies on charitable donations and funders, and as I have collected the whole story, I can provide relevant pieces for other teams to increase income for the hospice. By

showing an interest in the hospice's past, by default I've become custodian of the heritage archive, a responsibility which is quite an honour that I am trusted with the heritage and knowledge of the history.

## Heritage exhibition

I wanted to produce an audio visual piece of work in a public space for the community to connect with the hospice and provoke memories. I had visited the 9/11 memorial museum<sup>6</sup> in New York and found presentation of first-hand audio accounts, photography, audio and video clips, a breathtaking experience. I visited a local community-focussed art exhibition held in a Jamaican café in Colchester, Identities and Stories: Caribbean Takeaway Takeover, which featured audio clips taken from oral histories of people of the Windrush generation who made their homes in Essex. The common factors between the international large-scale high production exhibition in New York and the locally-funded community take on a national story, were the first-person narratives, coupled with the emotion of the physical locations of those stories, provoking empathetic engagement and response to the exhibitions. By hosting an exhibition about the hospice at the hospice I felt I achieved a similar impact for people connected with the local hospice, and from this experience and feedback from visitors, I gained confidence that there was interest in the project and that I had the material and the drive to do it again three years later for the hospice's 40<sup>th</sup> anniversary, opening it up to more people.

I commissioned a local designer, a colleague who had been made redundant during the pandemic who already knew about my research and plans for the exhibition, and

<sup>6 9/11</sup> Memorial and Museum, visited in October 2017 <a href="https://www.911memorial.org/">https://www.911memorial.org/</a>.

<sup>&</sup>lt;sup>7</sup> Identities and Stories: Caribbean Takeaway Takeover, visited in April 2018

<sup>&</sup>lt;a href="https://www.heritagefund.org.uk/our-work/identities-stories-caribbean-takeaway-takeover-essex">https://www.heritagefund.org.uk/our-work/identities-stories-caribbean-takeaway-takeover-essex</a>.

we visited Firstsite art gallery in Colchester to establish detail, preferences, sizing for the visuals, spacing between artwork, and how the exhibitions looked and felt to me as a visitor. Both Michael Landy's provocative *Welcome to Essex*<sup>8</sup> exhibition and his *Break Down: 20 Years*<sup>9</sup> were inspiring, particularly his use of press cuttings, photographs and video. *Art for Life: An exhibition made with key workers*<sup>10</sup> with its local healthcare connection and use of video interviews using digital tablets, was reassuring to see in action what I had planned as a similar interactive element as part of my Heritage exhibition.

The NLHF deadline had been revised because of the global circumstances but that new deadline was approaching; it was late summer and the exhibition needed to be ready by Hospice Care Week in October 2021. I didn't feel confident I could pull the exhibition off and worried it wouldn't be good enough or do justice to the people involved or even appeal to a wider audience. I was overwhelmed with the amount to cover and I knew there were more stories to be told but not enough time to capture before the exhibition. Yet, with determination and a sense of owing it to the interviewees and to myself, the artwork was finalised and printed, the audio edited and uploaded, and invitations sent.

With continuing restrictions and the vulnerability of the interviewees, I planned a small-scale exhibition in the hospice day centre which could be cancelled last minute if circumstances changed. The pandemic had taken its toll on staff and volunteers, so I created a reflective space overlooking the grade II listed hospice building,

<sup>&</sup>lt;sup>8</sup> Michael Landy, *Welcome to Essex Exhibition*, 2021 <a href="https://firstsite.uk/event/michael-landys-welcome-to-essex/">https://firstsite.uk/event/michael-landys-welcome-to-essex/>.

<sup>&</sup>lt;sup>9</sup> Michael Landy, *Break Down: 20 Years*, 2021 <a href="https://firstsite.uk/event/michael-landys-break-down-20-years/">https://firstsite.uk/event/michael-landys-break-down-20-years/</a>.

<sup>10</sup> Art for Life: An Exhibition Made with Key Workers, 2021 <a href="https://firstsite.uk/event/art-for-life/">https://firstsite.uk/event/art-for-life/>.

garden and pond to install the Heritage exhibition. A group of core people involved at the beginning attended together, resulting in an afternoon of nostalgia and reminiscence between friends and former colleagues, with the view of the hospice building creating a poignancy during the tail-end of a time of restricted human contact.

Will Quince, the Colchester MP at the time, had accepted my invitation to view but shortly before he was due to visit, his office called to cancel after the news that day of the murder of his colleague, Sir David Amess MP. Instead, he invited me to bring the exhibition to his community day at Firstsite gallery the following month. That event produced an emotional response from some of the visitors, with one commenting it had sparked precious memories for their mum who is living with dementia. I explored options of holding the exhibition in other locations within the catchment area post-pandemic, particularly to focus in Jaywick in the Tendring District where the Hospice and NLHF have an outreach interest, and which according to The English Indices of Deprivation 2019 was the most deprived neighbourhood in England. The Martello Tower on Jaywick Sands seafront has a quirky gallery space within the historic building for community heritage and arts which attracts tourists, so in spring 2022 the Heritage exhibition was opened to a wider audience.

Having had contact with the Oral History Society during the project, I was asked to write a piece about the exhibition which was published in the local projects section in

<sup>&</sup>lt;sup>11</sup> The English Indices of Deprivation 2019, p.5, 'The most deprived neighbourhood in England according to the IMD2019 is to the east of the Jaywick area of Clacton on Sea (Tendring 018a)', https://assets.publishing.service.gov.uk/media/5d8e26f6ed915d5570c6cc55/loD2019\_Statistical\_Rele ase.pdf.

the *Oral History Journal*.<sup>12</sup> Within weeks of the first exhibition, I gave a presentation about the project to delegates in a parallel session at the 2021 national Hospice UK conference in Liverpool, having initially submitted an abstract for a poster. The experience was both terrifying and exhilarating and firmed up my feeling that the pandemic had taken away my enthusiasm for the project at the time but after presenting the project to other hospices at the conference, I knew the project wasn't over and I could improve it by adding stories from people who experience the hospice's care.

## **Life Stories**

I shelved the Heritage project for a while because of personal and work commitments and by the time I resumed, the hospice was heading towards its 40<sup>th</sup> anniversary, and here was an opportunity to revisit the project after the restrictions and uncertainty of Covid had, frustratingly, limited the potential of the original exhibition. As it was milestone anniversary and because I had already tested the exhibition and was confident it was achievable and had public interest, I took this as an opportunity to introduce its history to more people by adding a new section to show the present day hospice by featuring people it supports 40 years on. I was interested in the patient as a person and not the diagnosis. When speaking with patients, I often hear them talking about their lives revolving around their illness, and not as the person who is still living and has memories and stories of a whole life lived. I wanted to give people a voice to feel they can be themselves again, not just what is on their medical record, hoping it would be a therapeutic experience at end of life and that the recordings would be beneficial for their future bereaved families.

<sup>&</sup>lt;sup>12</sup> Sarah Beer, 'Essex | St Helena Hospice Heritage Stories', *Oral History Journal*, 51 (2023), pp. 8–9.

With funding secured, I set about the Life Stories project to complement the Heritage and become a combined oral history exhibition to celebrate 40 years of St Helena Hospice in 2025; past and present.

#### Interviewing people at end of life

A key part of my role at the Hospice is asking patients to be photographed, filmed and to tell their stories about their hospice care. I am comfortable and confident doing that, however, asking people at end of life to reflect on their own life and leave their legacy for others to read or hear, was a different request and initially unfruitful. To begin with I had a produced a postcard briefly outlining the project, what would happen and how it would benefit both the patient and the hospice. I gave some to nurses visiting people at home and left some around the inpatient unit, and while the postcards alone did not yield participants, they were a useful follow up device to hand to patients after I verbally explained the project. Initially I'd said they would 'appear in an exhibition' and on hindsight, I should not have led with that as it sounded scary. After a few rejections, I framed the request differently, softly talking first about recording their thoughts for their families and then discussing using a very small part of that for the exhibition. Some participants came from introductions from my nursing colleagues and I could then phone the patient to discuss, but most people were engaged after speaking with them about general marketing stories and building trust with them to participate in the Life Stories project. Talking to patients was the most successful method; they could see I was not a threat, they could ask questions before deciding. Locations of the interviews were where they were receiving palliative care, hospice or home, and were longer in the patients' homes surrounded by their possessions and familiarity, and not interrupted by background

Hospice activity. I enjoyed interviewing in both environments and privileged they spoke with me when their remaining time is precious.

Patients I interview as part of my role at the Hospice usually seem to have accepted they are dying<sup>13</sup> as often the patient will be having counselling or spiritual care, and sometimes they have had a long illness with time to prepare. Generally, the patients I work with are 'pre-screened' as often they will have come from a clinical professional or I will have checked with a nurse or counsellor that they have capacity to understand and consent to my requests, and that they are in a place of wellbeing, and this is part of the hospice's ethics process. However, asking them to record an oral history of their own life story had a different reaction; they had to remember who they were before diagnosis and had to reflect on how their life used to be, rather than talking about their illness.

Their illness may have become the topic of conversation, <sup>14</sup> so it becomes natural to talk about themselves in a medical context and their experience of hospice care, this is discussed in chapter 2. Taking off that protective layer to reveal their vulnerable and frightened own self, knowing part of that would be on public display, possibly during their lifetime, certainly after their death, was challenging at times, but I learnt increased sensitivity when talking with patients when they don't have the protective barrier of talking about the hospice or their diagnosis. During recording, some patients knowing they were going to die soon, slightly gave away fear, sadness, resignation, by a change in the delivery of their words or facial expression. I felt remorseful that I had made them feel that way and at times I needed to debrief with

<sup>&</sup>lt;sup>13</sup> Anu Viitala and others, "I Am Still Valuable" – A Qualitative Study of Incurable Cancer Patients Coping in Hospice Care', *Scandinavian Journal of Caring Sciences*, 37.3 (2023), pp. 720–31. <sup>14</sup> The Lancet Oncology, 'Patient First; Person First', *The Lancet Oncology*, 24.10 (2023), p. 1053, doi:10.1016/S1470-2045(23)00465-5.

clinical staff, but every patient said how much they had enjoyed the experience and the opportunity to talk about things they had done and things that were important to them. Unprompted, a participant expressed gratitude for being heard as a person who had lived a fulfilling life and had achieved their ambitions, and not as the person who was labelled with an incurable illness experiencing pain and symptoms, a topic also discussed in chapter 2. This insight has inspired me to change the way I approach storytelling in my role, where although the focus is on the hospice experience as the goal is raise awareness of hospice services, going forward I will bring in more of the person's pre-diagnosis story.

For the bereaved families, the long-term impact of the Life Stories project will be beneficial, <sup>15</sup> particularly for the young children whose parents died during the project, with the recordings providing comfort and connection for them, as well as preserving family history. One family played some of the audio clip I recorded, at their loved one's funeral, another used photos I had taken on a screen at the wake, another told me how precious the recording was that they could hear their mum's voice again. The wife of a young patient desperately wanted her husband to record for the children's future, but the patient wasn't willing to accept they were end of life and declined the invitation to record. Since he died, I have recorded the wife talking about her husband's life as she agreed to be the focus of a fundraising campaign, and we both know a public record of their dad will be valuable for the children in the future.

<sup>&</sup>lt;sup>15</sup> Michelle Winslow, 'Taking Oral Histories to Improve End-of-Life Care', *Nursing Times*, 14 January 2015, Vol 111 No15 Edition, p. 21

<sup>&</sup>lt;a href="http://global.factiva.com/redir/default.aspx?P=sa&an=NURTIM0020150109eb1900006&cat=a&ep=ASE">http://global.factiva.com/redir/default.aspx?P=sa&an=NURTIM0020150109eb1900006&cat=a&ep=ASE</a> [accessed 29 August 2025].

I often reflect how I can't do my day job without something terrible having happened to someone else. 'Privileged' is a word that my nursing colleagues use to describe their role in a patient's life, and that is how I feel having being trusted to listen to someone's thoughts and memories and then present them to the public.

Challenges encountered during the project undoubtedly were dying and death. The reality of recording with patients at the end of life is that some planned interviews had to be cancelled last minute due to declining health and memory, tiredness, their remaining time and on occasion, death before the interview could take place.

Notable learning was the need to be ready and available when a patient wanted to record their memories and to be adaptable when circumstances change rapidly, not always practicable when there are deadlines and commitments of a simultaneous day job.

# The 40th anniversary exhibition

Combining the Heritage and Life Stories elements into one exhibition, *St Helena Hospice stories collection: Life Stories and Heritage exhibition*, I hoped would widen interest as the 40th anniversary was topical local news showing visitors where the Hospice started and who started it, and where it is now and who it serves.

Reflecting on the first Heritage exhibitions in 2021/22 and the joy and reminiscence it had brought to the invited guests, I had booked a large two-roomed gallery space at Firstsite for two days, one of which was the anniversary day, and in consultation with one of the Hospice's founders and an original nurse, invited an extended list of early staff and volunteers to a private viewing that afternoon to celebrate the 40<sup>th</sup> anniversary. Having the Heritage room filled with people who had made the hospice

what it is, chatting about their collective past, giggling at photos of themselves 40 years ago, and taking pride in their achievements, went better than I could have hoped for. As they were leaving, I said 'see you in five years for the next one', to which the response was they probably wouldn't still be alive then; a poignant reminder of why it had been important to do the project.

The gallery space next to the Heritage room housed the Life Stories. I'd produced a video of interviewees answering questions about life which played on a loop throughout the exhibition, and this held visitors captive and some stood and watched a complete loop which I hadn't expected. Firstsite staff told me they had unconnected visitors expressing that they had an emotional response to the video and the artwork, finding it uplifting but moving knowing the people pictured were nearing the end of life. I'd spent a lot of time with these people listening and laughing with them, so I had been desensitised to the emotional impact which someone seeing it for the first time experienced, especially for the people visiting the gallery without knowing this exhibition would be on. I'd taken portrait photos of the patients to show a hint of how they were living, deprived or wealthy, home or hospice, young or old. I wanted to show that people with incurable illness don't always look ill as most of the interviewees looked well, their condition only given away by hints such as the edge of a wheelchair or an oxygen tank. Witnessing the bereaved see and hear their loved ones in the gallery space was an emotional experience for me. Of the Life Stories interviewees, 11 had died by that time and of the remaining four, two were well enough to attend the Firstsite exhibition, bringing their families with them. Encountering them next to their photo and their video was poignant for me and their families, and the patients seemed at ease and happy to have left a legacy. Equally, the Heritage project will be beneficial long-term for the families of those involved as

they can listen to oral history recordings of their loved ones, hear their voices, and understand their involvement with the hospice.

#### Not the end

I felt happy to make the Heritage interviewees feel appreciated, and bittersweet for the bereaved families of the Life Stories people. It took seven years on and off to get to an exhibition I could be proud of, and on reflection I am glad it culminated in the 40th anniversary year of St Helena Hospice. The extra time and funding to add 'the present' Life Stories to the 'past' Heritage oral histories made more of an impact in the local community, the Hospice community, and on me. I learned more about the impact that storytelling and reminiscing has on wellbeing, particularly on patients telling their story and the impact on families having the legacy and will apply this to my role as storyteller at the hospice. I am thinking about how to incorporate Life Stories as a service for the hospice patients, and looking for funding, along the lines of the Sheffield oral history project. 16 I feel privileged to have produced a celebration of the Hospice's 40 year anniversary with a public exhibition in 2025 to inform, entertain, preserve and pay tribute to people who set up St Helena Hospice and to those who benefit from its work today.

The project started simply but became complex once the value of the oral histories and their potential was recognised and funding was involved. It became an allconsuming complex piece of work blurring the line between the MAD PaR and my job. The project has been a labour of love from me, pouring my own emotion into the exhibition at times, but it has strengthened relationships with my nursing colleagues

<sup>&</sup>lt;sup>16</sup> University of Sheffield, 'Oral History in Palliative Care - Oral History in Palliative Care - Research -Nursing and Midwifery - The University of Sheffield', n.d.

<sup>&</sup>lt;a href="https://www.sheffield.ac.uk/snm/research/oralhistory/main">https://www.sheffield.ac.uk/snm/research/oralhistory/main</a>.

as they have been very supportive of me with informal clinical supervisions. I care about the people involved; the founders and shapers of the early days of the hospice, the patients and families, and the unconnected people who viewed the exhibition and felt something about St Helena Hospice.

### **Dissertation**

#### Introduction

'You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.'

These words written by Cicely Saunders,<sup>17</sup> founder of the modern hospice movement, sum up her concept of total pain, that 'suffering encompasses all of a person's physical, psychological, social, spiritual, and practical struggles'.<sup>18</sup>
Saunders developed the idea that pain control was an important part of a good death, and as early hospices began to open, this was the subject being discussed by their clinical and medical teams. However, while the palliative care professionals were talking openly about dying and death inside hospices, social acceptance of discussing the topic outside these confines had become taboo in post-war Britain; a wider 'cultural denial of death'<sup>19</sup> grew following death on a mass scale during both wars. As Tony Walter wrote, 'adjusting to peacetime means leaving the past behind' and for the war bereaved, 'remembering as well as forgetting, speaking as well as refusing to speak'.<sup>20</sup>

With the post-war advent of NHS hospitals in 1948 followed by the beginning of the modern hospice movement in 1967, many people were dying of incurable illness out

<sup>&</sup>lt;sup>17</sup> Cicely Saunders, 'The Evolution of Palliative Care', *Patient Education and Counselling* (2000), citing her own article in The Nursing Times 'Care of the dying - 1: The problem of euthanasia', (1976) issue 26, pp. 1003-5.

<sup>&</sup>lt;sup>18</sup> 'Dame Cicely Saunders: A Palliative Care Pioneer | Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation | King's College London', n.d. <a href="https://www.kcl.ac.uk/cicelysaunders/about-us/cicely-saunders">https://www.kcl.ac.uk/cicelysaunders/about-us/cicely-saunders</a> [accessed 26 August 2025].

<sup>&</sup>lt;sup>19</sup> David Clark, 'To Comfort Always: Lessons from the Past to Inform the Future', Hospice UK conference, 2016 <a href="http://endoflifestudies.academicblogs.co.uk/to-comfort-always-lessons-from-the-past-to-inform-the-future-at-hospice-uk-2016/">http://endoflifestudies.academicblogs.co.uk/to-comfort-always-lessons-from-the-past-to-inform-the-future-at-hospice-uk-2016/>.

<sup>&</sup>lt;sup>20</sup> Tony Walter, On Bereavement: The Culture of Grief (Open University Press, 1999), pp.40-47.

of sight in hospitals, care homes or hospices, rather than the Victorian way of nursing the dying at home and carrying out traditional family mourning rituals.<sup>21</sup> Hospice care grew quickly from the first dedicated inpatient unit to more than 300 hospice projects 20 years later in 1987<sup>22</sup> helping people to 'live until they die'<sup>23</sup> and helping to make dying, death and bereavement more tolerable for patients and families, adding to the almost invisibility of the process for ordinary, non-medical people.

#### Not in conversation

If the process of dying and grief has been sanitised and taken away from the family since the NHS and hospices began, so too is the language and conversation around death. With death taken care of in institutions, palliative care doctor Kathryn Mannix argues knowing what to expect at end of life and recognising the patterns of the deathbed, is lost, and instead in post-war Britain people turn to popular culture for social cues.<sup>24</sup> Mannix addressed the taboo of death in a BBC video:

'We've stopped talking about dying; we've stopped mentioning the D words. Instead of saying dead we say passed or passed away; instead of saying dying we might say seriously ill. [...] We've lost the rich wisdom of human dying and it's time for us to talk about dying and reclaim the wisdom.' <sup>25</sup>

<sup>&</sup>lt;sup>21</sup> Patricia Jalland, *'Bereavement and Mourning (Great Britain)'*, International Encyclopedia of the First World War (WW1), pp. 187-242.

<sup>&</sup>lt;sup>22</sup> David Clark and others, *A Bit of Heaven for the Few? An Oral History of the Modern Hospice Movement in the United Kingdom* (Observatory Publications, 2005), p.220.

<sup>&</sup>lt;sup>23</sup> Shirley Du Boulay, *Cicely Saunders The Founder of the Modern Hospice Movement* (Hodder and Stoughton, 1998).

<sup>&</sup>lt;sup>24</sup> Kathryn Mannix, *With the End in Mind: Dying, Death and Wisdom in an Age of Denial* (HarperCollins, 2017), pp. 1-2.

<sup>&</sup>lt;sup>25</sup> 'Doctor Kathryn Mannix Argues It's Time to Break the Death Taboo', BBC, 22 August 2024 <a href="https://www.bbc.co.uk/videos/cx02l4p0e5wo">https://www.bbc.co.uk/videos/cx02l4p0e5wo</a> [accessed 26 August 2025].

Death-positive movements such as Death Cafes<sup>26</sup> and Compassionate

Communities<sup>27</sup> are found in small pockets of Britain, so palliative care professionals and people living with incurable illness are turning to popular media platforms to bring dying and death back into the consciousness and living rooms of British people. The popular podcast series *You, Me and the Big C*, hosted by people living with cancer, dedicated an episode to the language people use to describe death and dying, as presenter, Rachael Bland, said:

'We wanted to talk about it because people don't talk about it, and the reason we are all so scared of our cancer coming back and getting worse and going down that road, is because ultimately we are worried that it's going to kill us and it is that fear of death. I think very much in this country at the moment, we don't talk about death.' <sup>28</sup>

Hospices talk about a good death, assisted in part by advance care plans to record a patient's wishes about care, resuscitation, choices about their own death, to avoid a bad death and having some control over quality and preparedness for death.<sup>29</sup>
Hospice UK, a national champion for hospices, organises two annual campaigns, Dying Matters<sup>30</sup> and Hospice Care Week,<sup>31</sup> to undo public sensitivities of dying, death and bereavement that, arguably, hospices and the NHS created simply by being institutions where death happens behind walls. Of course, care for the dying and deaths in hospice inpatient units only account for a small part of the choice of

<sup>26</sup> 'Welcome to Death Cafe', n.d. <a href="https://deathcafe.com/">https://deathcafe.com/">[accessed 26 August 2025].

<sup>&</sup>lt;sup>27</sup> 'Compassionate Communities UK', Compassionate Communities UK, n.d. <a href="https://compassionate-communitiesuk.com/">https://compassionate-communitiesuk.com/</a>> [accessed 26 August 2025].

<sup>&</sup>lt;sup>28</sup> Rachael Bland, Deborah James, and Lauren Mahon, *You, Me and the Big C: Putting the Can in Cancer*, Series 2 episode 1 (August 2018), About Death.

<sup>&</sup>lt;sup>29</sup> Glennys Howarth, *Death and Dying: A Sociological Introduction* (Polity Press, 2007), p.148.

<sup>&</sup>lt;sup>30</sup> 'Dying Matters', Hospice UK, is a campaign to keep the conversation about dying, death and bereavement in the public eye, widely supported by hospices on a local level

<sup>&</sup>lt;a href="https://www.hospiceuk.org/our-campaigns/dying-matters">https://www.hospiceuk.org/our-campaigns/dying-matters</a> [accessed 26 August 2025].

<sup>&</sup>lt;sup>31</sup> 'Hospice Care Week', Hospice UK, raises awareness of what hospice care is and what hospices do. <a href="https://www.hospiceuk.org/hospice-care-week">https://www.hospiceuk.org/hospice-care-week</a>> [accessed 26 August 2025].

care and support hospices offer, with services at home often outweighing the small number of beds available in inpatient units. At St Helena Hospice in 2024/25, around 90% of its work is carried out where patients live,<sup>32</sup> while the 2023 national palliative and end of life care profiles show an increase compared to 2019 in home deaths (28.4% of deaths) and a decrease in hospice deaths (5.2% of deaths) while the majority of palliative deaths were in hospital (42.8% of deaths).<sup>33</sup>

## Cradle to the grave(ly ill)

The interwar years found Britain in a period of deprivation and during the Second World War a committee led by William Beveridge, whose 1942 report set out the need to address the hardships faced in order to thrive socially and economically; Want, Disease, Ignorance, Squalor and Idleness.<sup>34</sup> With a change of government in 1945 to Labour under Prime Minister Clement Atlee, the newly appointed Minister of Health, Aneurin (Nye) Bevan, outlined proposals for a National Health Service (NHS) where everyone was to have the right to medical treatment. The introduction of the NHS in July 1948 had promised free medical care from the cradle to the grave for the whole population, yet the focus of the welfare state was firmly on widespread health problems in a post-war society trying to rebuild, rather than attending to people at the end of life.<sup>35</sup>

<sup>&</sup>lt;sup>32</sup> St Helena Hospice Annual Report (2024).

<sup>&</sup>lt;sup>33</sup> 'Palliative and End of Life Care Profiles January 2025 Update: Statistical Commentary', GOV.UK, n.d. <a href="https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary">https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary</a> [accessed 26 August 2025].

<sup>&</sup>lt;sup>34</sup> Dr Michelle Clement, *The Founding of the NHS: 75 Years on – History of Government*, 13 July 2023 <a href="https://history.blog.gov.uk/2023/07/13/the-founding-of-the-nhs-75-years-on/">https://history.blog.gov.uk/2023/07/13/the-founding-of-the-nhs-75-years-on/</a> [accessed 26 August 2025].

<sup>&</sup>lt;sup>35</sup> David Clark, 'Two Reports That Shaped the History of End of Life Care in the United Kingdom', *End of Life Studies*, 29 August 2014 <a href="http://endoflifestudies.academicblogs.co.uk/two-reports-that-shaped-the-history-of-end-of-life-care-in-the-united-kingdom/">http://endoflifestudies.academicblogs.co.uk/two-reports-that-shaped-the-history-of-end-of-life-care-in-the-united-kingdom/</a>.

The war had taken lives but the NHS set out to keep people alive; modern doctors and modern medicine were about cure, not to ease the process of dying.<sup>36</sup> Medical intervention gives the impression, as Jupp and Gittings wrote, 'death has been conquered and the NHS would sooner or later find cures for everything'.<sup>37</sup> In his Cradled to the Grave? paper David Clark writes there was no interest in terminal care as a clinical subject, and no strategic or operational guidance on the dying other than from charitable organisations in the first 20 years of the NHS.<sup>38</sup> The 1950s was a decade where the NHS was finding its feet but away from the new health and welfare systems, research and reports<sup>39</sup> about lack of care of the dying were being published. One of them, a landmark study carried out by the Joint National Cancer Survey Committee of the Marie Curie Memorial Foundation and the Queen's Institute of District Nursing concluded, after researchers visited more than 7,000 patients who were being nursed at home, there was a need for residential homes for patients as there was grave neglect, poor housing, no water, no heating, isolation, and no hope anything could be done for them. 40 The second influential report came at the end of the 1950s with a survey of terminal care in the UK carried out by Brigadier Glyn Hughes which showed deficiencies of terminal care in the NHS, including in homes for the dying.<sup>41</sup> Society by the end of the 1950s was beginning to understand there was a problem in the care available and given to the incurable, and a new way of

<sup>&</sup>lt;sup>36</sup> Shirley Du Boulay, *Cicely Saunders The Founder of the Modern Hospice Movement* (Hodder and Stoughton, 1998), p.78.

<sup>&</sup>lt;sup>37</sup> Death in England: An Illustrated History, ed. by Peter C Jupp and Clare Gittings (Manchester University Press, 2001), p.271.

<sup>&</sup>lt;sup>38</sup> David Clark, 'Cradled to the Grave? Terminal Care in the United Kingdom, 1948-67', *Mortality*, 4.3 (1999), pp. 225–47, doi:10.1080/713685979.

<sup>&</sup>lt;sup>39</sup> Clark, 'Two Reports That Shaped the History of End of Life Care in the United Kingdom', discusses a joint committee of the Marie Curie Memorial and the Queen's Institute of District Nursing investigating the needs of people living with cancer at home, published in 1952; and a second prepared by Dr H L Glyn Hughes containing 'a description of current provision for the care of the dying, together with recommendations for development'.

<sup>&</sup>lt;sup>40</sup> Du Boulay, *Cicely Saunders*, p.81.

<sup>&</sup>lt;sup>41</sup> Du Boulay, *Cicely Saunders*, p.81.

thinking about palliative care began to emerge. Cicely Saunders had collected clinical and narrative data from more than 1,000 patients and was developing ground breaking techniques in pain control and publishing papers about her work and findings, including her first paper on terminal care in St Thomas's Hospital Gazette in 1958.<sup>42</sup> A movement focussed on improving care for the dying and the bereaved was beginning to emerge and by 1964 Saunders had published a paper using the term *total pain* for the first time.<sup>43</sup>

### Caring to the end

The opening of the first modern hospice, St Christopher's Hospice, in 1967 proceeded to offer an alternative to the failings of the NHS in the care of the dying, but in a time of a new free healthcare system in the UK, hospices could have seemed to the public as a step backwards given the need to raise their own funds and rely on charitable, church and philanthropic donations. Indeed, as reported in the next chapter, the local newspaper in north east Essex published a letter to the editor complaining about 'nurses rattling tins'. <sup>44</sup> Locally too, there was some opposition to hospice care from doctors, who allegedly refused requests from their own patients to go there, <sup>45</sup> and across the UK there were medical professionals who were sceptical of the pain management system of regular drug giving, developed by Saunders and used in the new hospices, for fear patients would become addicted or tolerant of them. <sup>46</sup> The opening of St Christopher's in 1967 marked growing international thinking about palliative care, such as Elisabeth Kübler-Ross, whose work alerted

<sup>&</sup>lt;sup>42</sup> Cicely Saunders, 'Dying of Cancer', St Thomas's Hospital Gazette, 56.2 (1958), pp. 37–47.

<sup>&</sup>lt;sup>43</sup> Clark and others, A Bit of Heaven for the Few, p. 219.

<sup>&</sup>lt;sup>44</sup> 'Letter to the Editor', *Essex County Standard*, 28 December 1979.

<sup>&</sup>lt;sup>45</sup> St Helena Hospice Heritage Project, w. Dr Elizabeth Hall, Oral History Recording (2018).

<sup>&</sup>lt;sup>46</sup> Du Boulay, *Cicely Saunders*, p.70.

American society to death and dying, including her observations on the five stages of dying: denial and isolation, anger, bargaining, depression, acceptance.<sup>47</sup> By the end of the 1970s it was accepted the principles of hospice care could not only be in specialist units but through day services and at home too, and by 1981 a report in the British Medical Journal showed there were 58 hospice inpatient units, 32 home care teams and eight hospital support teams offering 'specialist services for terminal cancer' in the UK.<sup>48</sup>

The hospice movement reached Essex in the early to mid-1980s with Chelmsford Hospice Service (now Farleigh Hospice) registering in 1982 as a sitting service, and Saint Frances Hospice opening in 1984. To the north of the county, a steering group was set up in 1979 with the idea of establishing hospice care for Colchester and Tendring, which would open its doors as St Helena Hospice to its first inpatient on 20th May 1985. The building had capacity to admit 15 patients at a time from across its north east Essex catchment area and run a hospice in the home service, which had been started four years earlier with two Macmillan nurses.

Hospice care matters to the people who experience it, as Dr Elizabeth Hall, one of the principal founders of hospice care in north east Essex, said during an oral history interview for the *St Helena Hospice Heritage Project*:

'You go there to live until you die, and the whole idea of helping people live until their last breath and for the family to be involved and supported, all this time later is still something that people don't realise until they've actually experienced it.'49

<sup>&</sup>lt;sup>47</sup> Elisabeth Kübler-Ross, *On Death and Dving* (Routledge, 1973, c1970).

<sup>&</sup>lt;sup>48</sup> Barry Lunt and Richard Hillier, 'Terminal Care: Present Services And Future Priorities', *British Medical Journal (Clinical Research Edition)*, 283.6291 (1981), pp. 595–98 <a href="https://www.jstor.org/stable/29503396">https://www.jstor.org/stable/29503396</a>> [accessed 26 August 2025].

<sup>&</sup>lt;sup>49</sup> St Helena Hospice Heritage Project, w. Dr Elizabeth Hall, 2018.

The project explored the history of St Helena Hospice through oral histories and formed part of an exhibition held in May 2025 to celebrate the 40th anniversary of its opening, combined with the Hospice's Life Stories Project of lived memories recorded with patients. Oral history is rooted in recording, preserving and interpreting people's memories and voices, and as the method focuses on open-ended questioning which provokes recollection, emotion and gives a platform to hear what is important and significant to the interviewee, it was chosen as the method for this research because the aim of the project was to tell a story and give a voice<sup>50</sup> to people who shaped the Hospice and to the people who use its services 40 years on, after all, as Alessandro Portelli wrote, 'oral historical sources are narrative sources'.51 Oral history is not just narrative, commentary or telling a story, it relies on the memories and perspectives of an interviewee, including their opinion and interpretation of an event or period of time, which can be a strength and a weakness as a reliable source, as discussed in chapter 2. These unique and emotional recollections of the establishing and experiencing hospice care in north east Essex position the project within the wider field of oral history as a primary resource for other research in hospice care, healthcare, local history and family history.

In the preface to the fourth edition of The Voice of the Past, 40 years after first published, Paul Thompson acknowledges that the influence of digital communications means oral history is more commonly practiced now, and that oral history and life stories can be presented in the media and exhibitions.<sup>52</sup> The focus of the recorded interviews and presentation was created mindful that an audience can

<sup>&</sup>lt;sup>50</sup> Paul Thompson and Joanna Bornat, *The Voice of the Past: Oral History* (Oxford University Press, 2017).

<sup>&</sup>lt;sup>51</sup> Alessandro Portelli, 'What Makes Oral History Different', in *The Oral History Reader*, 3rd ed. (Routledge, 2015), p. 51.

<sup>&</sup>lt;sup>52</sup> Thompson and Bornat, *The Voice of the Past*.

easily access and consume vast content online. The goal was to tell the story of St Helena Hospice past and present in an engaging way and so a journalistic style of recording oral history was adopted in producing the exhibition to reflect the way content is consumed, and to engage an audience unfamiliar with hospices and unfamiliar with oral history. As discussed in chapter 2, there are similar techniques in both fields<sup>53</sup> and there was room to diversify methods for this project, particularly as the researcher has experience shorter length interviews with a quick turnaround for public viewing<sup>54</sup> and using soundbites and imagery to create an emotional response. A large-scale national oral history account of the modern hospice movement carried out by the Hospice History Project over 10 years,<sup>55</sup> gave an insight into what was possible with a local-level project to preserve the voices of people in a variety of roles who cared about making the end of someone's life as comfortable.

By the time of the exhibition, stories and memories captured for the St Helena Hospice projects had brought richness and colour to the process of establishing an organisation, reminding the audience there were people at the heart of it, and bringing life to the organisation with the people who use its services 40 years later.

The collecting of oral histories and photography throughout the projects was underpinned by robust ethical considerations and approved by the University of Essex (*Ethical Approval of Research Involving Human Participants*) and St Helena Hospice Ethics Committee, as highlighted in the accompanying Documentation of Creation. Additional considerations for the duty of care to patients was carried out and involved discussion with clinical or medical professionals to make sure the

<sup>&</sup>lt;sup>53</sup> Feldstein, 'Kissing Cousins'.

<sup>&</sup>lt;sup>54</sup> Evan Faulkenbury, 'Journalism, COVID-19, and the Opportunity of Oral History', *The Oral History Review* (Abingdon), 47.2 (2020), pp. 253–59, doi:10.1080/00940798.2020.1791723.

<sup>&</sup>lt;sup>55</sup> Clark and others, A Bit of Heaven for the Few.

person had capacity to participate and understand how the material and data gathered would be used.

The next chapter follows the origin of St Helena Hospice through the firsthand stories collected, newspaper reports and documents, followed by a look at the methodology of oral history; memory, the use of journalism in the project and its connection with oral history, oral history in a palliative care setting, and presenting oral history.

The 40<sup>th</sup> anniversary milestone of St Helena Hospice was a fitting opportunity to curate *St Helena Hospice stories collection: Heritage and Life Stories exhibition* and preserve the stories and voices of people connected with its past and present, which aimed to educate and engage the local community, perhaps for the first time ever, perhaps for the first time since a loved one died under its care, or perhaps because they were receiving hospice care when visiting.

## Chapter 1

### Origin of hospice care in north east Essex

'Well, it came about really because several people unknown to each other, could see that we could do looking after who we then called the terminally ill people, much better.'56

To tell the story, the local newspapers, meeting minutes and leaflets produced by the Hospice steering committee are all interesting and useful sources to consider in addition to the oral histories recorded for the *St Helena Hospice Heritage Project*.

Dr Elizabeth Hall had just returned from a holiday and was sitting in her garden with a cup of coffee looking through the Essex County Standard and saw there was going to be a public meeting about whether there was a need for a hospice in Colchester.<sup>57</sup> Dr Hall, who was working in the oncology department at Essex County Hospital, had previously heard Cicely Saunders speak and had herself been thinking about the idea of a hospice for a while too so went along to the meeting to hear what was being discussed:

'I'd actually totted up how much money I thought we needed and I think it was £250,000 which of course we needed about a million and a half by the time we'd finished!'58

The Essex County Standard reported<sup>59</sup> around 130 people had packed out the public meeting at Colchester Town Hall, which was introduced by former Colchester Mayor Cllr Joyce Brooks, and that by the end a 15-strong steering committee had been set

<sup>&</sup>lt;sup>56</sup> St Helena Hospice Heritage Project. 2018.

<sup>&</sup>lt;sup>57</sup> St Helena Hospice Heritage Project, 2018, description taken from oral history w. Dr Hall.

<sup>&</sup>lt;sup>58</sup> St Helena Hospice Heritage Project, w. Dr Elizabeth Hall, 2018.

<sup>&</sup>lt;sup>59</sup> Stuart Buckman, 'Meeting Backs Plan To Build Hospice for Town', *Essex County Standard*, 10 July 1979.

up. The article gave an account of proceedings, documenting the first speaker as Dierdre Allen, who was a sister at Myland Hospital and had studied hospices. Her colleague, consultant physician Dr Peter Kennedy, gave his view on the ability of the NHS to provide a personal touch for the dying, adding that people have to be cared for as individuals, 'not as part of a huge sausage machine'. In an interview 40 years later, Dr Kennedy recalled the public meeting:

'We were amazed at so many people coming to this first meeting which was almost a call to arms; arms and alms! The response was enthusiastic; people realised the idea of a hospice was to be very necessary and was well supported.' <sup>60</sup>

The Soroptimists, led by Irene Overton, were also present as club member Dianne Couch, a long serving volunteer at the Hospice, remembered:

'The fundraising appeal became one of the first major projects the club was involved in because we raised the first thousand pounds to pay for the meeting in the Moot Hall that got the thing underway.' <sup>61</sup>

While it appeared the majority were in favour of a hospice, the Essex County Standard reported a note of warning from the floor by a former nurse who warned 'the hospice could become a ghetto'.<sup>62</sup> The article also noted the gathered attendees heard from cancer specialist, Dr George Rhys-Lewis, who warned the hospice would have to be careful it was not 'used as a dumping ground' and that the 'NHS should have no claim on it'.

A few days after the meeting, councillor Joyce Brooks phoned Dr Elizabeth Hall to ask if she would like to chair the steering committee to get it off the ground, as Dr

<sup>60</sup> St Helena Hospice Heritage Project, w. Dr Peter Kennedy, Oral History Recording (2019).

<sup>&</sup>lt;sup>61</sup> St Helena Hospice Heritage Project, w. Dianne Couch, Oral History Recording (2020).

<sup>62</sup> Buckman, 'Meeting Backs Plan To Build Hospice for Town'.

Rhys-Lewis had turned down the role. It was July 1979 and it would be another six years before St Helena Hospice opened. The committee quickly revealed the name St Helena Hospice, chosen in keeping with the legend of Colchester's connection with the saint<sup>63</sup> and that hospices were built on a Christian foundation of bringing 'relief and release from all that de-humanises men and women in every area of experience [...] hospice care embraces all beliefs and non-believers without question'.<sup>64</sup>

Both the first public meeting and early information leaflets produced by the steering committee addressed the issue of funding, first explaining the entire capital cost of the Hospice project had to be found, it would not be a private hospital, and although some beds would be funded by the Area Health Authority, but the balance would have to be found from trusts, foundations and individuals. Saunders had chosen for St Christopher's Hospice to be independent of the NHS for 'freedom of thought and action,'65 and the hospice movement followed this thought. However, there was some opposition locally to the idea of the Hospice being run on charitable donations, with letters to the newspaper editor being a source of evidence of public feeling, 66 as one reader wrote to the Essex County Standard: 'Aneurin Vevan, the architect of today's health service, thought that he had seen the last forever of what he saw as an obscenity – the sight of nurses collecting on street corners with little flags and

<sup>63</sup> website Colchester City Council, 'The Borough Arms', Colchester City Council, n.d.

<sup>&</sup>lt;a href="https://www.colchester.gov.uk/info/cbc-article/?catid=town-hall-heritage&id=KA-01743">https://www.colchester.gov.uk/info/cbc-article/?catid=town-hall-heritage&id=KA-01743</a>

<sup>&</sup>lt;sup>64</sup> Various public information leaflets produced by the St Helena Hospice Steering Committee, 1979-1980.

<sup>65</sup> Du Boulay, Cicely Saunders p. 90.

<sup>&</sup>lt;sup>66</sup> Andrew Hobbs, A Fleet Street in Every Town (OpenBook publishers, 2018), p.352.

collection boxes'.<sup>67</sup> Another letter, although praising the Hospice campaigners, felt 'funds should be made available for the NHS to provide this necessary service'.<sup>68</sup>

Newspapers covering rural and town communities have been an integral part of local life helping people feel part of a community within their geographical area<sup>69</sup> and the local journalists from the Essex County Newspapers Ltd group played a key role in the success of the collective positive public groundswell of support for the idea of a new hospice in the area. Allan Crabtree volunteered on the Hospice's council of management with the role of liaising with the press and public:

'When I sat back and I looked at it I thought, well I've got no product, I've got nothing, no intelligence, and I'm trying to sell it, which is a bit difficult.' <sup>70</sup>

Local journalist Bill Tucker would often write about the Hospice project's progress in his column *Tucker's Topics*, and his colleague Wyn Jones, who amongst his articles about the Hospice, wrote about St Christopher's Hospice to explain to the people of north east Essex what a hospice would be like.<sup>71</sup> One of the directors of Essex County Newspapers at the time was Michael Ellis who, while an inpatient at St Helena Hospice in 2019, recorded his memories of the appeal to bring hospice care to the area:

'They were already beavering away this idea of a hospice when I got here, so I encouraged it, and eventually, it was quite remarkable and it's poignant because it couldn't happen now, principally because in Colchester the local

<sup>&</sup>lt;sup>67</sup> Letter to the Editor, Essex County Standard, 28 December 1979.

<sup>68</sup> Letter to the Editor, Essex County Standard, 14 January 1980.

<sup>&</sup>lt;sup>69</sup> Rasmus Kleis Nielsen, *Local Journalism: The Decline of Newspapers and the Rise of Digital Media* (I.B. Tauris, 2015), p.16.

<sup>&</sup>lt;sup>70</sup> Allan Crabtree, *St Helena Hospice Heritage Project*, Oral History Recording (2018).

<sup>&</sup>lt;sup>71</sup> Wyn Jones, 'Treating The Dying With Dignity', Essex County Standard, 20 July 1979.

people and the press supported the idea and raised the money, but that was kind of what the local press did.' 72

In May 1980 an appeal for £250,000 was launched and fundraising began in earnest with a swell of support within the Colchester community, not least from a group of friends and neighbours who called themselves the Cherrydale Weavers, blending the names of their street addresses. The friends saw the benefits of bringing hospice care to the area, as group member Pat Adams described:

'We had we had a young lady who lived just down the road and she breast cancer, and unfortunately her treatment was not up to standard and she eventually died. She was in agony and we think that if there'd been a hospice about at that moment, she would been able to be treated and cared for and she would have had a much happier end of life, and that's really how we started [...] when we first started though, we used to go every weekend to some sort of fete or anything like that and if we raised £30 pounds in a whole day we were over the moon!' 73

The Hospice project in north east Essex had encouragement from Cicely Saunders, who in June 1980 replied to a correspondence from Dr Elizabeth Hall outlining the plans, 'I am really very grateful to you for setting out exactly what is going on in Colchester. You really are developing in the way that one hopes to see among the various people who are trying very hard to start hospice work around the country.'<sup>74</sup> Her letter advised contacting the National Society for Cancer Relief as 'they will sometimes fund Macmillan nurses to start work in a community area'<sup>75</sup> and in July

<sup>&</sup>lt;sup>72</sup> Michael Ellis, St Helena Hospice Heritage Project, Oral History Recording (2019).

<sup>&</sup>lt;sup>73</sup> St Helena Hospice Heritage Project, w. Pat Adams, Oral History Recording (2019).

<sup>&</sup>lt;sup>74</sup> David Clark, *Cicely Saunders - Founder of the Hospice Movement, Selected Letters* 1959-1999 (Oxford University Press, 2002), p.203.

<sup>&</sup>lt;sup>75</sup> Clark, Cicely Saunders - Founder of the Hospice Movement, Selected Letters 1959-1999, p.203.

the following year, two Macmillan nurses were indeed funded by the Society to provide specialised care at home for the 'terminally ill'.

St Helena Hospice was incorporated in August 1980 and the steering group was replaced by the council of management, and in May 1981 the organisation was registered as a charity. Meanwhile, the council of management were searching for a property to convert into a hospice building, which was thought would be quicker than a new build, with grounds and easy access to travel to across the area it was to serve, when appeal organiser Mary Fairhead, who was out on a visit in her role as councillor, spotted an old house behind some brambles:

'I couldn't wait to get home to phone Joyce [Brooks], I said 'I think I've found it!' The developer French Keir were using it as their headquarters as all the building work on the houses would be going around it. So we put it to the committee and we had few months of upset because we didn't know how to get the money [...] and one day I went to Elizabeth's to pick up the biscuit tin where we put the appeal donations when they came in, opened up the tin and there was one bulky envelope from a company trust with cheques for £40,000, I couldn't believe my eyes! I rang Elizabeth and I think we both shed a tear. it meant we could carry on'. <sup>76</sup>

As the project went on, the fundraising target increased considerably and the council of management, after much deliberation, appointed a paid fundraiser and administrator, Pat Gosling, as it could not be done by volunteers alone.<sup>77</sup> From then on, the fundraising and stewardship of people raising money out in the community became more coordinated, as secretary Joy Higgins remembered:

<sup>&</sup>lt;sup>76</sup> Mary Fairhead, *St Helena Hospice Heritage Project*, Oral History Recording (2019).

<sup>&</sup>lt;sup>77</sup> St Helena Hospice Heritage Project, w. Dr Elizabeth Hall (2018).

'I can see it now, the room upstairs, it was full of donations, all sorts of things and masses and masses of volunteers. It was just amazing actually [...] you got caught up in it, it was just amazing how the money came in, really.'<sup>78</sup>

In February 1983 planning permission was approved to convert the grade II listed Myland Hall<sup>79</sup> and the building was acquired and in a ceremony in the grounds in November 1983, the Duchess of Norfolk cut the first sod to begin the building work. Local carpenter Colin Bruce worked on the building site:

'We never knew anything about a hospice, it was somewhere we'd heard that people go to die and with that, you know, if you got cancer, this is where you were going to end up. It was a bit poignant when we put the morgue in, you think well...'80

Myland Hall had stood empty since 1972 when a compulsory purchase was made to make way for a new housing estate, driving out the Impey sisters who lived there.

Their niece Angela d'Angibau has volunteered in the Hospice garden since 1985, maintaining the Impey Border along the driveway:

'My grandmother, Isabel Impey, was given Myland Hall by her father, Wilson Marriage, in 1910. I have many happy memories of skating on the pond, playing in the garden. It was a very happy house, a very busy house. They had cows, so in the war we always had milk and butter and cream, and there were mulberries and quinces in the garden; we were very lucky.'81

Once the building work was nearing completion, a team of volunteers transformed the grounds into a calm and reflective garden space to be enjoyed by patients and

<sup>&</sup>lt;sup>78</sup> Joy Higgins. St Helena Hospice Heritage Project. Oral History Recording (2019).

<sup>&</sup>lt;sup>79</sup> John S Appleby, St Helena Hospice Alias Abbots Hall, Myland Hall or Mile End Hall, Colchester (c2001).

<sup>80</sup> Colin Bruce, St Helena Hospice Heritage Project, Oral History Recording (2021).

<sup>81</sup> Angela d'Angibau, St Helena Hospice Heritage Project, Oral History Recording (2020).

visitors, and is a space where some patients choose to die. The gardeners were led by Margaret Farrow, a former nursing colleague of Dr Hall:

'I remember seeing Myland Hall for the first time, I don't think that concerned me, I thought it was a lovely site for a hospice, my biggest concern was when Pat Gosling said to me "I think you should start the garden"; I thought, where do I start? The pond was my biggest worry [...] because the pond froze hard, the winter was incredibly cold, absolute solid ice.'82

Although St Christopher's Hospice had opened 12 years before, the nursing discipline of palliative care in a modern hospice setting was still in its infancy nationally. In the two weeks before St Helena Hospice opened, its first nurses were having intensive training having come from other types of nursing, in particular in the use of regular drugs to prevent pain reasserting, central to the model of care developed by Cicely Saunders.<sup>83</sup> Dr Elizabeth Hall, who was by then Medical Director, and nurse Dierdre Allen trained some nurses in the dining room at Dr Hall's home. Training and development was ongoing, an important part of Saunders's vision for hospices,<sup>84</sup> and the new medical and clinical staff began to understand the concept of total pain; the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.<sup>85</sup>

On 20<sup>th</sup> May 1985, the first patient was admitted, 22 year old Lisa Brenchley, who had been living with a brain tumour, and her dad Brian Brenchley remembered:

'They were still finishing the place off, it was all very, very new. It was literally only just opened and they got her in right away. My memories of first going

<sup>82</sup> Margaret Farrow, St Helena Hospice Heritage Project, Oral History Recording (2023).

<sup>&</sup>lt;sup>83</sup> Shirley Du Boulay, *Cicely Saunders The Founder of the Modern Hospice Movement* (Hodder and Stoughton, 1998), p.70 and throughout.

<sup>84</sup> Du Boulay, Cicely Saunders.

<sup>85</sup> Glasgow End of Life Studies, 'University of Glasgow - Total Pain', n.d.

<sup>&</sup>lt;a href="https://www.gla.ac.uk/research/az/endoflifestudies/projects/totalpain/">https://www.gla.ac.uk/research/az/endoflifestudies/projects/totalpain/>.

into the Hospice are a little vague, I do remember being aware that she would be the only patient there, wondering if she would be lonely. My expectation was that it would be like a newly opened hospital, being very clinical and regimented, I could not have been more wrong!'86

The impact of the first patient stayed with Sue O'Neill, at the time a 26 year old staff nurse, and decades later she recalled welcoming Lisa:

'She was a very young lady, younger than me and I thought wow, the impact of that, she will never be my age [...] I learned very quickly about listening to the patient; not to medicalise the illness and the diagnosis but to listen to them and their story.'87

Six years after the idea of bringing hospice care to north east Essex was mooted at the Town Hall in Colchester, St Helena Hospice was up and running, however, some local GPs refused to send their patients to the Hospice and forbade them to contact the Hospice themselves, even if in pain.<sup>88</sup> Yet despite some opposition, it was a proud moment for the people who worked tirelessly to make it happen, as Dr Hall recalled:

'I'd gone all over the country looking at different hospices, looking at what I thought was good practice and wherever I went, people were telling me "I feel so safe here, how wonderful it is here", and I thought I wonder how long it's going to be before somebody says "I feel so safe here". And it was within 48 hours I should think, which was wonderful.'89

<sup>86</sup> Brian Brenchley, St Helena Hospice Heritage Project, Oral History Recording (2019).

<sup>87</sup> St Helena Hospice Heritage Stories, with guest Sue O'Neill (2020)

<sup>&</sup>lt;a href="https://soundcloud.com/sthelenahospice/st-helena-hospice-stories-podcast-episode-1">https://soundcloud.com/sthelenahospice/st-helena-hospice-stories-podcast-episode-1</a>.

<sup>88</sup> Dr Elizabeth Hall, St Helena Hospice Heritage Project, 2018.

<sup>89</sup> St Helena Hospice Heritage Project, w. Dr Elizabeth Hall (2018).

## Chapter 2

'Sailing... sailing makes me happy. It's the feeling you get, just the wind pushing you along. I like the freedom, you can go to places no one else can go. The peace and quiet and being lost in the world is lovely.'

St Helena Hospice stories collection: Life Stories and Heritage exhibition was created from two oral history projects – Heritage and Life Stories – and featured a selection of excerpts from interviews recorded with current patients and people who established the organisation 40 years ago. Oral history was a fitting method for a project about an organisation rooted in listening, giving people nearing end of life an opportunity and the time to talk. While the Heritage part of the St Helena Hospice project was focused on events around a specific time period, 1979 to 1988, and how the interviewee fit into that, Life Stories recordings were personal reflections or life review; a subtle difference, Joanna Bornat argues, between oral history and reminiscence.<sup>90</sup>

### Memory and oral history

Memory played a role in both parts of the project with a risk of inaccurate recall; in the case of the Life Stories interviewees, they were patients between the ages of 27 and 90 whose medications and conditions may have influenced memory, and likewise the age of some of the Heritage interviewees, who ranged from 62 to 92 years and a few were also receiving palliative care. However, the projects were about the stories behind and within St Helena Hospice, feelings rather than facts and so the resulting exhibition were about colour, richness and life. While recording

<sup>&</sup>lt;sup>90</sup> Joanna Bornat, 'Reminiscence and Oral History: Parallel Universes or Shared Endeavour?<sup>1</sup>', *Ageing and Society*, 21.2 (2001), p. 223.

voices can tell the story of a specific moment or a whole life, as Portelli said, 'the first thing that makes oral history different, therefore, is that it tells us less about events than about their meaning'.<sup>91</sup>

Some of the St Helena Hospice heritage project interviewees were guarded in some of their accounts, possibly keeping in mind they were talking to someone currently employed by the Hospice or that they were aware of the recorder therefore not wishing to break confidentiality or ruffle feathers among other people who had been involved. In this situation, both the interviewee and interviewer playing their subjective roles and colliding to shape the encounter with each other, described as intersubjectivity, devising 'appropriate performances' in response.<sup>92</sup>

Memory is at the core of oral history where an interviewee may recall a story or perspective unique to them and how they felt about it then and feel about it now. Criticisms of oral history in the early 1970s were, according to Alistair Thompson, that deterioration in health, nostalgia as people age, the way other people remember events, or retrospect could influence memory. The interviewee may interpret a past experience or embellish their role in it, or have retold the story enough times for the narrative to have changed to fit with the way they verbally deliver it. Some voices recorded for the Heritage project recalled some of the events and other people's involvement in setting up St Helena Hospice slightly differently, so it becomes 'an oral history and not the oral history's as noted by Clark et al in a collection of oral

<sup>&</sup>lt;sup>91</sup> Alessandro Portelli, 'What Makes Oral History Different', in *The Oral History Reader*, 3rd ed. (Routledge, 2015), p.52, pp. 48–58.

<sup>92</sup> Lynn Abrams, Oral History Theory (Routledge, 2016), pp.58-77.

<sup>&</sup>lt;sup>93</sup> Alistair Thomson, 'Making the Most of Memories: The Empirical and Subjective Value of Oral History', *Transactions of the Royal Historical Society*, 9 (1999), p.291.

<sup>94</sup> Portelli, 'What Makes Oral History Different', p.53.

<sup>95</sup> Clark and others, A Bit of Heaven for the Few p.6.

histories documenting the hospice movement. Nevertheless, as discussed in the next section, other sources could fill in the blanks in the Hospice's historical timeline. While memory in oral history can be seen as a weakness, it can also be seen as a strength as it brings up emotion and personal thoughts of the interviewee and what matters to them. As Lynn Abrams writes "an oral history source based on memory offers up insights into the interplay between the self and society, between past and present and between individual experience and the generalised account; in addition, it will often provide emotional content that a written version of the same story will not."

### Journalism and oral history

Where details, dates and order of events which resulted in a hospice for north east Essex had become hazy for interviewees of the St Helena Hospice Heritage project, local newspapers, early annual reports, meeting minutes and public information leaflets filled the gaps in the organisation's history and could be cross-referenced. Portelli argues while some historians disregard the method of oral history, they still use its transcripts which 'in a lesser measure (thanks to the frequent use of shorthand) this applies to parliamentary records, minutes of meetings and conventions, and interviews reported in newspapers: all sources which are legitimately and widely used in standard historical research'.

As discussed in the previous chapter, the local journalists at the time had supported the campaign to bring hospice care to north east Essex, publishing articles delving

<sup>96</sup> Abrams, Oral History Theory, p81.

<sup>&</sup>lt;sup>97</sup> David Clark and others, *A Bit of Heaven for the Few? An Oral History of the Modern Hospice Movement in the United Kingdom* (Observatory Publications, 2005) *'It can be particularly rewarding to consider interviews alongside the letters or articles and reports written at the time of the events'* p. 7.
<sup>98</sup> Portelli, 'What Makes Oral History Different', p. 53.

into what a hospice would be like and highlighting the fundraising efforts of the committee and of local people, while their editors gave many column inches and positive headlines to the cause. Local newspapers have been an important part of the areas they serve since they began 'chronicling events from the mundane to the monumental' and helping people feel part of a community and connected.<sup>99</sup> The historic news coverage fills in the memory gaps of the interviewees and gives names of people otherwise forgotten, therefore combining journalism with oral histories and inhouse publications from the early 1980s gives a rich and rounded picture of what happened and how the community felt.

With Essex County Newspapers titles so proactive and positive in following the story of the Hospice's inception, the question of bias<sup>100</sup> comes into play as well as the need to sell copies and advertisements.<sup>101</sup> By the early 1980s, the hospice movement in the UK was growing rapidly and being widely reported<sup>102</sup> in the communities they were starting to appear in, publishing engaging content on the provocative topic of dying and death likely to sell papers and advertising.

Newspapers historically have swung to a political side or used influence to publicise local debates<sup>103</sup> or to back a campaign for change, in this case a change to the way people were cared for at end of life, as Mike Ellis, a director at Essex County Newspapers during the 1980s, recalled:

'Because I come from that era when everybody had a granny in the attic, we knew what happened to old folk and we knew there was a need, you know, for

<sup>&</sup>lt;sup>99</sup> Rasmus Kleis Nielsen, *Local Journalism: The Decline of Newspapers and the Rise of Digital Media* (I.B. Tauris, 2015), p. 1.

<sup>&</sup>lt;sup>100</sup> Denise Bates, *Historical Research Using British Newspapers* (Pen and Sword, 2016), chapter 5. <sup>101</sup> Mark Feldstein, 'Kissing Cousins: Journalism and Oral History', *The Oral History Review*, 31.1 (2004), pp. 1–22.

<sup>&</sup>lt;sup>102</sup> 'British Newspaper Archive', Search 1967-1980, n.d.

<sup>&</sup>lt;a href="https://www.britishnewspaperarchive.co.uk/">https://www.britishnewspaperarchive.co.uk/>.</a>

<sup>&</sup>lt;sup>103</sup> Nielsen, *Local Journalism*, pp. 1–3.

people to end their lives with as much comfort as could be mustered. And that was it really, it was just that feeling that if you are a civilised local community, you need one [...] And it was a good example of how the local press can make things happen.'104

Mistakes in reporting is a limitation of using historical articles, as shown in the research about St Helena Hospice with the spelling of key names varying between articles, along with alleged inaccurate reporting in the Essex County Standard of a comment made at the 1979 public meeting and subsequent letters to the editor. Errors could be made as the copy went through not least the writer, subeditor and editor, or an interviewee may have inadvertently given incorrect information to the journalist in the first place. 106

Journalism played a role in the audio and video recordings and presentation of the *St Helena Hospice stories collection: Life Stories and Heritage exhibition* as the researcher/ curator drew on their own work experiences using soundbites and imagery with the aim of creating an emotional retrospective that would appeal to visitors. The idea that journalists and oral historians are related and can use each other's techniques to improve, is a topic discussed by Mark Feldstein, who describes them as 'kissing cousins' using similar interview equipment, carrying out background research, making the interviewee feel comfortable, starting with a direct open-ended questions, listening and asking follow up questions – related but separate, with room to diversify their methods. <sup>107</sup> While some oral historians, like Evan Faulkenbury who explored the two fields in the context of Covid-19, agree there are similarities but neither has embraced each other fully: for oral historians to do shorter length

<sup>&</sup>lt;sup>104</sup> St Helena Hospice Heritage Project, w. Michael Ellis (2019).

<sup>&</sup>lt;sup>105</sup> 'Letter to the Editor', Essex County Standard, 28 December 1979.

<sup>&</sup>lt;sup>106</sup> Bates, Historical Research Using British Newspapers chapter 2.

<sup>&</sup>lt;sup>107</sup> Feldstein, 'Kissing Cousins', P. 5.

interviews, prepare less, and do a quicker turnaround ready for public view; for journalists to do more thorough oral history interviews and make the transcript available in full.<sup>108</sup>

The immediacy of a global event such as the Covid pandemic with ordinary people sharing their stories online, presented an opportunity 'for oral history to record, preserve, and share history—not years down the line but right now.'109 For the St Helena Hospice Heritage Project, interviews with the founders conducted as events were happening have their place as an 'instant history'110 but which now fill the gaps decades later when memories and detail have faded.

### Palliative care and oral history

The Life Stories project, which featured in the 40<sup>th</sup> anniversary exhibition in 2025, was focussed on patients of St Helena Hospice who were nearing end of life and experiencing care in their homes across north east Essex or in the inpatient unit in Colchester. It is important to note increased ethical considerations were discussed with each patient's clinical lead such as mental and emotional capacity before approaching them for interview following the Hospice's usual procedures and policies, and if needed, a follow-up conversation post-interview with the clinical lead, particularly if there were signs of distress. The majority of the interviews remains private for the patients and families, with a soundbite selected from each recording by the researcher to produce a written quote and short audio and/or clip in collaboration, which would be shared publicly with informed consent. None of the 15

<sup>&</sup>lt;sup>108</sup> Evan Faulkenbury, 'Journalism, COVID-19, and the Opportunity of Oral History', *The Oral History Review* (Abingdon), 47.2 (2020), pp. 253–59.

<sup>&</sup>lt;sup>109</sup> Faulkenbury, 'Journalism, COVID-19, and the Opportunity of Oral History', p. 254.

<sup>&</sup>lt;sup>110</sup> Feldstein, 'Kissing Cousins', p. 4.

interviews were deposited with Essex Sound and Video Archive, however selected audio and video clips are available on the St Helena Hospice website.<sup>111</sup> Above all, the story is their story and belongs to them.

Hospice care embraces the spiritual and emotional needs of a patient as well as the physical, and Cicely Saunders is well-documented as listening to and collecting narratives of patients to support her work in understanding what a patient needs at end of life, which she used to educate clinical and medical professionals. <sup>112</sup> In a chapter called 'A voice for the voiceless', Saunders wrote: 'I know that listening to a patient's own tale of their troubles can be therapeutic in itself. As another patient said, 'It seemed the pain went with me talking'. <sup>113</sup> It is common to see clinical and medical staff at St Helena Hospice listening to patient's stories and indeed these staff-patient relationships led to some of the participants of the Life Stories project, as Michelle Winslow noted when developing an oral history project at the Sheffield Macmillan Unit for Palliative Care, 'staff were keen to refer patients to us as they thought the process was therapeutic, with end-of-life patients regaining a sense of control and autonomy'. <sup>114</sup> Listening to a person's narrative has developed in other settings, <sup>115</sup> including some care homes where healthcare staff found it was beneficial for both sides, and taking a biographical approach with residents helped them deliver

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<sup>111</sup> St Helena Hospice Life Stories (n.d.) <www.sthelena.org.uk/lifestories>.

<sup>&</sup>lt;sup>112</sup> David Clark, *Cicely Saunders: A Life and Legacy* (Oxford University Press, 2018), p.137.

<sup>&</sup>lt;sup>113</sup> Barbara Monroe and David Oliviere, *Patient Participation in Palliative Care: A Voice for the Voiceless* (Oxford University Press, 2003), pp. 3–8.

<sup>&</sup>lt;sup>114</sup> Michelle Winslow, 'Taking Oral Histories to Improve End-of-Life Care', *Nursing Times*, 14 January 2015, Vol 111 No15 Edition, p. 21.

<sup>&</sup>lt;sup>115</sup> Andrew Moore and others, "I Am Closer to This Place"—Space, Place and Notions of Home in Lived Experiences of Hospice Day Care', *Health & Place*, 19 (2013), pp. 151–58.

person-centred care and build better relationships when they saw 'the person behind the patient'. 116

Life Stories participants spoke about a range of life events, memories, family, achievements, and feelings as they looked back on their lives and loves at their most vulnerable time. According to research gathered from work with patients at the palliative care unit in Sheffield, the potential benefits of oral history with people receiving palliative care include raised self-worth, attaching meaning to life experiences, and recognition and validation. The 15 participants in the Life Stories project all expressed positive reactions to the experience, recognising their own story and its place in the world, 118 remembering their lives before diagnosis, before becoming their diagnosis when conversations become centred around their illness. their pain, their medication, their appointments, and no longer about their self. An article in The Lancet published in 2023 explained when doctors refer to someone only as a cancer patient 'by using disease-first language such as this, one can dehumanise the patient, equating them with their disease rather than referring to them as an individual.'119 A qualitative study on end of life care in Finland published the same year, found patients receiving hospice care accepted they were dying and focussed on positive thinking and facing life, noting, 'even while entering the last phase of their lives, the participants felt that the disease did not define them and that

<sup>&</sup>lt;sup>116</sup> Amanda Clarke, Elizabeth Jane Hanson, and Helen Ross, 'Seeing the Person behind the Patient: Enhancing the Care of Older People Using a Biographical Approach', *Journal of Clinical Nursing*, 12.5 (2003), pp. 697–706.

<sup>&</sup>lt;sup>117</sup> Michelle Winslow, Karen Hitchlock, and Bill Noble, 'Recording Lives: The Benefits of an Oral History Service', *European Journal Of Palliative Care*, 16.3 (2009), pp. 128–30.

<sup>&</sup>lt;sup>118</sup> Joanna Bornat, 'Reminiscence and Oral History: Parallel Universes or Shared Endeavour?<sup>1</sup>', *Ageing and Society*, 21.2 (2001), p. 238.

<sup>&</sup>lt;sup>119</sup> The Lancet Oncology, 'Patient First; Person First', *The Lancet Oncology*, 24.10 (2023), p. 1053.

they still had all their dignity left [...] and they were doing everything in their power to enhance their well-being.'120

One participating Life Stories patient said they were delighted the researcher thought their life was worthy of sharing, and another expressed how honoured they felt to be part of the project and how they enjoyed the time spent speaking about their life. The wellbeing benefits of oral history for someone who knows their time is limited, reaffirms identity and values and a sense of purpose, as being listened to without a medical agenda and having time to express their past self, can be validating and dignified. In giving a person a voice 22 at end of life, they were presented with an opportunity to gain inner wellbeing from the process. The interviewee's personal composure, as Penny Summerfield explained, depends on the narrator's state of mind, conditioned for example by how secure she feels about the value of her life, what kinds of memories the moment of recall stimulates, and how the audience for reminiscence responds.

For family and friends, the voice recordings of their deceased loved one can support with their grief, <sup>124</sup> or perhaps help them understand the person better, why they did certain things, why certain things were important to them. Feedback from bereaved family members and friends of patients participating in the Life Stories project, was positive, emotional and thankful for the audio recording so they could hear their voice

<sup>&</sup>lt;sup>120</sup> Anu Viitala and others, "I Am Still Valuable" – A Qualitative Study of Incurable Cancer Patients Coping in Hospice Care', *Scandinavian Journal of Caring Sciences*, 37.3 (2023), pp. 720–31. <sup>121</sup> Michelle Winslow and Sam Smith, 'Supporting Older People in Palliative Care with Oral History', unpublished paper delivered at Dying for change: evolution and revolution in palliative care, Hospice UK National Conference (Liverpool, 20 November 2019).

<sup>122</sup> Thompson and Bornat, *The Voice of the Past*.

<sup>&</sup>lt;sup>123</sup> Penny Summerfield, *Histories of the Self* (Routledge, 2019), p.109.

<sup>&</sup>lt;sup>124</sup> Michelle Winslow and Sam Smith, 'How Does Providing an Oral History at the End of Life Influence Well-Being of the Individual and the Bereaved?', Poster Presentations, *BMJ Supportive & Palliative Care*, 4.Suppl 1 (2014), pp. A16–A16.

again,<sup>125</sup> and for the value of featuring their loved one in the exhibition and accompanying booklet so other people could know their person too. One family played this recorded clip of their loved one's voice at their funeral:

'Some of my happiest memories, well, the happiest memories, have been associated with the sea. We travel a lot to Scotland in our camper van where you can literally camp on a beach in certain places. What is it about it? It's about association. It's about the colour, it's about the movement. There's something very refreshing about the sea. Something quite healing about it.'126

### **Presenting oral history**

Excerpts of recordings from both projects were the basis of the 2025 *St Helena Hospice stories collection: Life Stories and Heritage exhibition* which was designed for visitors to feel the history<sup>127</sup> of their local Hospice instead of simply reading it, and to feel something for the people who use its services today<sup>128</sup> and to create a sense of belonging and connection.<sup>129</sup>

The exhibition was created drawing on elements of journalism combined with oral history. While the grammar and dialect of the speech was left in written quotes on the artwork, the essence of the person and the delivery of their story can become lost in transcription and strip out the sound of the voice, the silences, laughter and tone<sup>130</sup>; 'Oral sources are *oral* sources', as Portelli said, 'transcript turns aural objects into visual ones, which inevitably implies changes and interpretation.' However,

<sup>&</sup>lt;sup>125</sup> Winslow, 'Taking Oral Histories to Improve End-of-Life Care'.

<sup>&</sup>lt;sup>126</sup> St Helena Hospice Life Stories Project, w. Viv Ashley (2024).

<sup>&</sup>lt;sup>127</sup> Christine Gundermann, Key Terms of Public History (2025) pp. 33–35.

<sup>&</sup>lt;sup>128</sup> Gundermann, Key Terms of Public History pp. 45–46.

<sup>&</sup>lt;sup>129</sup> Amelia Scott, *The Exhibition Economy* (2025).

<sup>&</sup>lt;sup>130</sup> Shelley Trower, 'Authority, Reading, and Listening to Digital Oral Histories', in *Sound Writing: Voices, Authors, and Readers of Oral History*, ed. by Shelley Trower (Oxford University Press, 2023) p. 136.

<sup>&</sup>lt;sup>131</sup> Alessandro Portelli, 'What Makes Oral History Different', in *The Oral History Reader*, 3rd ed. (Routledge, 2015), p. 49.

visitors also had the opportunity to hear the voices of the interviewees, and in some case see on video, which especially in the case of bereaved family and friends, was emotionally valuable. Accessing the voices came via an interactive element of the exhibition fed from recordings housed online which are available on the St Helena Hospice website<sup>132</sup>. There are ethical questions when making recordings available on digital platforms including what listeners may do with them and whether interviewees would hold back some personal stories knowing they would be heard by strangers.<sup>133</sup> That said, the use of digital storytelling is fast growing since the advent of podcasting and the 'explosion of audio and video interviews now accessible online'.<sup>134</sup> In the case of both Hospice projects, the use of the recordings was explained to participants ahead of interview and a recording agreement signed, and with Life Stories, only an approved excerpt would be made publicly available with the rest given to them or their family on a memory stick for private use.

The choice of quotes and audio clips displayed at the exhibition were selected by the curator/ researcher to reflect the telling of the Hospice story in chronological order but from personal perspectives or to feel uplifting and life-affirming. According to Paul Thompson and Joanna Bornat, there are five ways to present oral histories: single life story narrative; a collection of stories; narrative analysis; reconstructive cross-analysis; polyphony and dialogue, described as 'organising fragmented extracts from the voices to create a new overall pattern around the theme.' 135 The St Helena Hospice exhibition presented oral histories through a collection of stories to

<sup>&</sup>lt;sup>132</sup> St Helena Hospice Heritage (n.d.) <www.sthelena.org.uk/heritage>; St Helena Hospice Life Stories (n.d.) <www.sthelena.org.uk/lifestories>

<sup>&</sup>lt;sup>133</sup> Trower, 'Authority, Reading, and Listening to Digital Oral Histories', p. 137.

<sup>&</sup>lt;sup>134</sup> Trower, 'Authority, Reading, and Listening to Digital Oral Histories' p. 138, paraphrasing a Michael Frisch essay '*From A Shared Authority to the Digital Kitchen, and Back*' (2011). <sup>135</sup> Thompson and Bornat, *The Voice of the Past* pp. 361–362.

give a broad look at the origin of the organisation, combined with polyphony and dialogue, leaving the storyteller to tell their story without interpretation by the curator but for the visitor to take from it what they interpret, and therefore can be seen as cocreated by speakers, authors and readers.<sup>136</sup>

Accompanying the written quotes and sound recordings in the Heritage section was a selection of photographs from the Hospice archives to provoke further reminiscence, and be a snapshot of the time period for visitors unfamiliar with the early 1980s. Accompanying Life Stories were portraits of the interviewees taken at the point of recording in order for visitors to physically see the person behind the voice and perhaps break down a few myths about who hospice care is for, such as for older people whereas the starting age of the participants in this project was 27. The visual was important in both elements of the exhibition with image and story intertwined, as Alexander Freund and Alistair Thomson wrote in the introduction to a collection of essays: 'Oral history and photography intersect at important epistemic points: evidence, memory, and storytelling.' 137

The exhibition blended emotions at the object (how interviewees felt) and subject (how visitors felt) level, or emotionalization as described by Gundermann: 'emotions at the object level are mixed with those at the subject level and can no longer be cleanly separated.' A private viewing of the exhibition on the Hospice's 40<sup>th</sup> anniversary day in 2025 for Heritage interviewees and other people involved at the beginning, gave them a collective experience and a shared reaction to events from a period of time that was important to them. As Joanna Bornat wrote 'for reminiscence,

<sup>&</sup>lt;sup>136</sup> Shelley Trower, *Sound Writing: Voices, Authors, and Readers of Oral History* (Oxford University Press, 2023).

<sup>&</sup>lt;sup>137</sup> A. Freund and A. Thomson, *Oral History and Photography* (Springer, 2011) p. 2.

<sup>&</sup>lt;sup>138</sup> Gundermann, Key Terms of Public History pp. 38–55.

the bonus to be gained from oral history is recognition of the significance of the told story and its place in the history of a particular life, community and society.' 139

In the neighbouring exhibition room where Life Stories was displayed, an impromptu collective emotional experience was witnessed between two bereaved families and a patient and their family, all unknown to each other, as they shared a personal moment between them. As one Life Stories interviewee said:

'All I care about is that my family is OK and they're looked after so everyone's able just to get on and just be family and focus on the family stuff.' 140

<sup>&</sup>lt;sup>139</sup> Bornat, 'Reminiscence and Oral History'.

<sup>&</sup>lt;sup>140</sup> Daisy Murfin, St Helena Hospice Life Stories Project (2023).

#### Conclusion

In the pages before, we have seen the period of time from diagnosis to death has increased over the last 75 years thanks to the NHS giving earlier diagnosis and medical intervention, and how better palliative care from hospices showed the NHS how to care for people to the end. We have seen death and dying is often not in conversation in the 21st century Britain, but conversations with people who are dying, matter.

Oral history recordings of the origin of St Helena Hospice matter to the people involved in bringing hospice care to north east Essex, giving them a chance to reflect on their role in an organisation that cares for people at the most vulnerable time of their life, and preserving their achievement for generations to come. Their recordings matter to the Hospice itself because they capture multiple voices of the events leading up to its opening and the early days, richly telling the story of its history. They matter to the people who work and volunteer at the Hospice now, particularly as a stretched NHS relies more on their work now at the same time as financial struggles are felt across hospices nationally, as it teaches them they have a shared heritage in a pioneering movement that gives comfort and dignity to people at end of life.

Oral history recordings of people using St Helena Hospice services matter to the individual telling their story, giving them a chance to reflect on a life lived, to be seen and heard and recognised as a person and not a diagnosis, and to find peace and wellbeing. Those recordings matter to the bereaved, whose loved ones' voices will be heard again. Their recordings matter to the Hospice itself because they are a reminder it exists to bring comfort for the people who face end of life. This research project contributes to discussion and interest in the benefits of oral history with

people experiencing palliative and end of life care with first-hand accounts from a north east Essex hospice, as participants anecdotally confirmed recalling parts of their loves and sharing memories and thoughts was beneficial to their self identity and wellbeing, and left a legacy for their loved ones.<sup>141</sup>

The *St Helena Hospice stories collection: Heritage and Life Stories exhibition* was a collective experience for the interviewees, the curator/ researcher, and the visitors who listened to and read the stories. By featuring past and present personal stories and thoughts of ordinary people, visitors to the exhibition had an opportunity to be educated about St Helena Hospice and the people it supports now, or to have an emotional response, whatever that may be, as they found something or someone to identify with.

Preserving the stories of where St Helena Hospice came from and the people it cares for, will become more valuable as time goes on. The recordings show a change in the way it operates and has grown and adapted over its 40 years and looking to the future, the landscape for hospices is changing; there is more pressure to support the NHS, without additional funding, and hospices are part of national debate on the role they could play in assisted dying. Stories of people who set up the Hospice are precious as they are part of the heritage of the hospice movement, regardless of what it has become or where it is going.

<sup>&</sup>lt;sup>141</sup> Michelle Winslow and Sam Smith, 'OA19 Can Oral History in Palliative Care Influence the Well-Being of Participants and the Bereaved?', Oral and Workshop Abstract Submissions, *BMJ Supportive & Palliative Care*, 5.Suppl 1 (2015), pp. A6–A6, doi:10.1136/bmjspcare-2015-000906.19.

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# **Appendices**

Appendix A Information sheet and consent form

Appendix B Photos of the exhibitions

Appendix C Heritage Collection booklet

Appendix D Life Stories Collection booklet

Appendix E Heritage artwork panels

Appendix F Life Stories Heritage artwork panels

# Appendix A

Information sheet and consent form

#### An oral history of St Helena Hospice

### Purpose of the research

Sarah Beer is researching an oral history of St Helena Hospice for a Masters by Dissertation in History at the University of Essex. The purpose is to capture the stories of the people who made it happen, and those who continue its work or benefit from it. The oral histories may be used in a temporary installation, and will later be donated to St Helena Hospice for its historical archives and for its promotional use to raise awareness of the work of the hospice.

## Usage of the audio / film / transcript / photo

- Stories captured on audio or film will be part of a digital archive for historical preservation
- The stories will also be transcribed and summarised, published, and digitally stored
- The stories will form a temporary installation of public history accounts about the hospice
- If a photograph is taken of you, this may be used alongside your story as above
- Stories captured may be used in entirety, or edited, or short quotes/ soundbites used, or a combination
- The footage/ audio along with transcript and summary, and photos, will be donated to the
  hospice for historical preservation and may be used publicly in full or in part, by or for the
  hospice, online or in print, at any time in the future

#### Consent

Your consent will be recorded on camera or audio recorder before the interview takes place. Additionally you will be asked to sign the consent form at the end of this information sheet. It will be stored as part of the research but will not be made public. A copy will be left with you.

In consenting to share your story and image as part of this research, you are agreeing for it to be made public, and acknowledging you will not receive any payment for your story or image now or in the future, or be given any special treatment by the hospice because of it.

#### Data access, storage and security

Personal data such as your address, phone number, email and any background notes will be stored electronically with password protection and stored on a password-protected computer. The principal investigator will be the only person accessing this information.

#### **Further details**

Sarah Beer is employed by St Helena Hospice, however, this research is being carried out as part of an independent study and it is not funded by the hospice.

### **Contact principal investigator**

Sarah Beer, History research student (Masters)

sb18112@essex.ac.uk

c/o Department of History, University of Essex, Wivenhoe Park, Colchester CO4 3SQ

# **Consent / Recording agreement**

Project title: An oral history of St Helena Hospice

Please initial or tick box

I confirm that I have read and understand the information sheet provided for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in this study is voluntary and that I am free to withdraw at any time, without giving a reason.	
I understand that the interview will be digitally recorded and then transcribed.	
I understand interview or parts of it will be used as part of a temporary installation celebrating the history of St Helena Hospice.	
I agree for the recording and transcript of the interview to be deposited the St Helena Hospice archive and that it may be used by the hospice at any time in the future.	
I consent for my contact details to be held by the Principal Investigator in a password protected file on a password protected computer for two years for the purposes of invitation to the installation.	
Restrictions and considerations:	
Participant's name (printed):	
Participant's signature:	
Date:	

# Appendix B

# Photos of the exhibitions



Heritage collection Studio 2, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025





Heritage collection Studio 2, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025

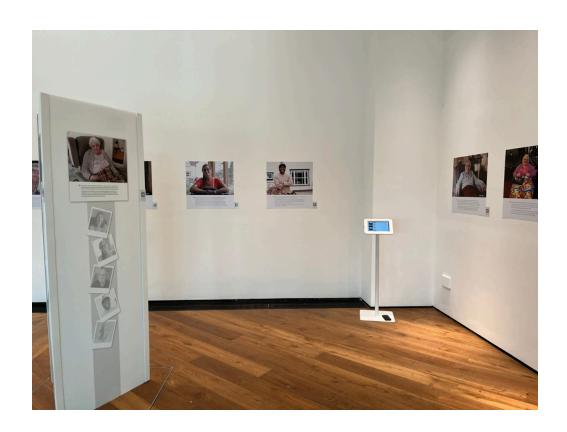




Dr Elizabeth Hall next to a photo of her at St Helena Hospice 1985 Heritage collection Studio 2, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025



Jane Elliot next to a photo of her at St Helena Hospice 1985 Heritage collection Studio 2, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025

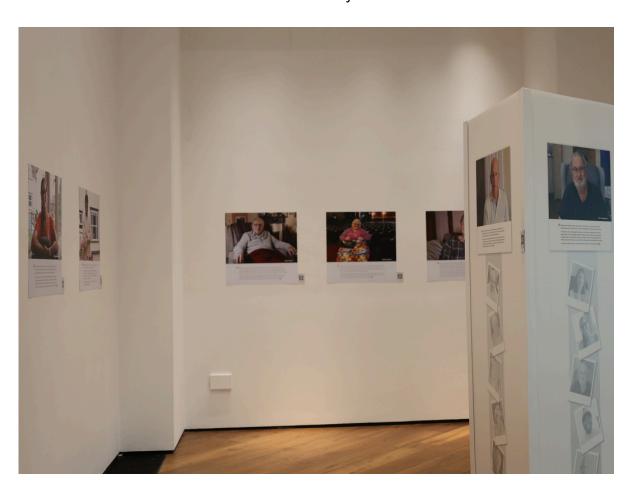


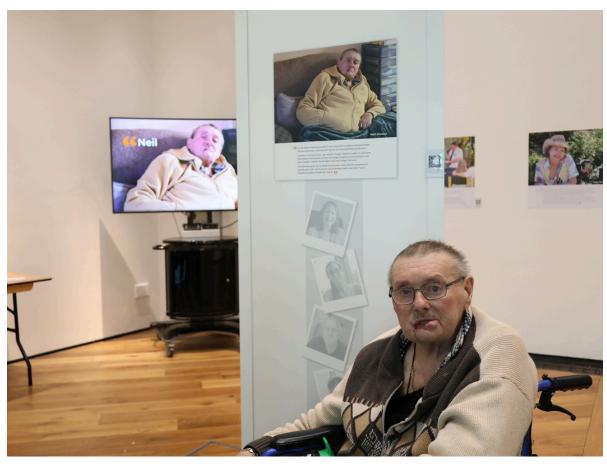
Life Stories collection Inner Mosaic, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025





Life Stories collection Inner Mosaic, Firstsite 20<sup>th</sup> and 21<sup>st</sup> May 2025





Neil, next to his artwork, Life Stories collection Inner Mosaic, Firstsite, 20<sup>th</sup> and 21<sup>st</sup> May 2025



Rod, next to his artwork, Life Stories collection Inner Mosaic, Firstsite, 20<sup>th</sup> and 21<sup>st</sup> May 2025



Heritage and Life Stories collection Jaywick Martello Tower 1<sup>st</sup> May to 22<sup>nd</sup> June 2025







Heritage and Life Stories collection Jaywick Martello Tower 1<sup>st</sup> May to 22<sup>nd</sup> June 2025





Heritage and Life Stories collection Jaywick Martello Tower 1<sup>st</sup> May to 22<sup>nd</sup> June 2025



# Appendix C

Heritage Collection booklet

# a stories collection











St Helena Hospice welcomed its first patient, 22 year old Lisa Brenchley, on  $20^{\rm th}$  May 1985.

It had taken six years of planning, fundraising and construction before the doors to the hospice building opened for the first time.

66 St Helena Hospice heritage stories ## is a collection of oral histories, photographs and video, spanning 1979-1988, from the people who volunteered their time, skills and passion to bring hospice care to Colchester and Tendring. The project is supported by The National Lottery Heritage Fund, thanks to National Lottery players.

www.sthelena.org.uk/heritage



St Helena Hospice came about because several people could see that we could be looking after people who we then called 'terminally ill', much better.

I saw in the paper councillor Joyce Brooks was holding a public meeting about the idea of a local hospice. I thought great, I'll just go along and see what's happening. A few days later I had a phone call to ask if I would chair the steering committee.

With better understanding and symptom control people could be helped to face their future honestly. There is, as Cicely Saunders said, an emphasis on helping people to *live* until they die.

Dr Elizabeth Hall, steering committee chair, council of management

Pictured: Dr Elizabeth Hall and Dr Phil Murray, oncology department, Essex County Hospital

A PUBLIC meeting to be held in the Colchester Town Hall tomorrow night could be the start of a hospice for the terminally Ill in Colchester.

A great number of people who hear of a

hospice think it is just another type of hospital.

In fact, it is a great deal more: It helps the dying to prepare themselves for death, and the living to come to terms with their loss. Sister Deirdre Allen, who works in the Myland Hospital in Colchester, has studied hospices and has done an eight-week course at St Anne's Hospice in Manchester.

LIDA HANSLEY talked to her about the very specialised care a hospice can give.

# A PLACE WHERE DYING HAS NO STIGMA



. Sieser Dearthé Allen, one of

the professional medical peo-

ple involved in getting a hos-

DEATH is the last tabou un a

Therefore, until the last few years since hospices became an accepted part of the health service, the terminally ill were selfconsciously ignored.

"Not everybody wants to talk about death after they have been told that they are terminally ill," says Sister Deirdre Allen.

And in a hospice, the whole object is to keep people involved in living right up to the point of dvine

dying.

"At St Anne's we had people who would go to the afternoon Bingo game and die that eight. It is certainly not what I would choose to do, but they were happy and isvolved right up to the mament of their death — which is what a hospice is all about.

"Of course some people think home is the place to die, but there are some like myself but would hats to be cared for by

"Being totally dependent on the family totally changes your relationship with them, and I would hate that. "Besides, there is a great deal of abser physical hard work in nursing the terminally ill, and soil every family could do it.

There are the things like the east amounts of laundry, the sleepless nights, the turning of patients, not being able to pop out and do the shopping.

"In a hospice, families are encouraged to visit at any time, so that patients certainly are not non-abandoned by their families. with

"It's just that the hospice does most of the hard, specialised work to make the patient free from pain. The family can anjoy the patient in a way which they did before he are she hecame ill.

"Working in a hospice is not a bit depressing, but the staff really have to want to do it.

"When I went on the course to St Anne's, we had a very happy set, but I heard that others had not been so happy because they had been sent to do the course rather than volunteering.

"That's why the Colchester bospice should be a charitable trust and not within the NHS.

The service would just send staff, and I don't think the community atmosphere would be the same."

One of the main developments after the hospice movement started in the early 1960s was the amount of research on pain control.

Now the dying can be kept free from pain, but drug dosages are so finely adjusted that there is none of the druwsiness associated with overdoaste.

"A bospice allows people to die with dignity and honesty," says Stater Allen. "But not everyone who goes tato a hospice dies. I worked in a 20-bod ward, and in the time I was there, for eight weeks, we had ten who didn't change. 14 who died and eight want home substantially better than when they came in.

"Some people stay for a long time — we had two cases of causer where the cancer had travelled and been deposited on secondary sites. But because, I believe, of the good care, the ladies were utill there, happy and alive, three vears later.

" But the average stay in a hos-

ff. pice is about three to s

"People differ in their reactions to death. Some refuse to talk about it and just don't want to know; others want to talk.

"Some patients are very afraid of death, but the fear and the physical symptoms of death can be coped with — the pain, the vomiting and the sleeplessors are all under control in the patients.

We help them to prepare themselves for death. Nobody died in lear and terror at the hospice.

"A hospice is truly a community affair. Voluntary workers are needed. We had 200 at St. Anne's, who do the flowers, the drinks, man the awtichboard after hours and at weekends, and generally have very definite duties.

"Working in a hospice is getting back to real nursing. In a let of hospitals these days, the enty interesting patients are those on respirators.

"In a hospice, one is involved again with the physical aspects of nursing care. It is very reward-

Tomorrow night's public meeting starts at 8 pm. The outcome for patients with lung cancer on the chest ward was pretty grim and they needed to be looked after in their terminal days. It became apparent to sister Deirdre Allen that we needed more than our few beds and we were amassing more and more patients as time went by. Deirdre went off on a course at a hospice in Manchester and came back convinced we needed a hospice.

Deirdre approached Joyce Brooks and arranged for a public meeting to be held. We were amazed so many people came to this first meeting which was almost a call to arms; arms and alms!

Dr Peter Kennedy, consultant with special interest in respiratory diseases, Myland Hospital

Image: Evening Gazette, 5th July 1979

# **MEETING BACKS PLAN**

# STUART BUCKMAN

A PACKED public meeting has pledged support for a hospice for the terminally ill in the Col-

About 130 people, including many from the medical world, launched the scheme by setting up a 15-strong

But a note of warning was sounded from the floor. A former nurse warned that the hospice could become a

Former Colchester Mayor Mrs Joyce Brooks opened the meeting by saying hospital resources were stretched to the limit.

She introduced Sister Deirdre Allen, of Myland Hospital, who has studied hospices and worked at St Anne's hospice in Man chester, and explained the role of a hospice in the care

"They are about caring for people and their families. and being cared for in pleasant surroundings by people who think that is the work they went to do." she

Raising the money would be a long job. She hoped people would keep up their

Consultant physician Dr Peter Kennedy said: "Death is one of the most moortant events in our He compared it to what lifetimes, and there are many people these days for whom the last few days now a prayer of healing. are unpleasant, lonely. humiliating and full of pain. And this cau be avoided." The Scroptimists have

#### MACHINE

He said many people could not rely on family support and help. Debilitating iliness could hit anybody, and there was no reason.

they could not be helped. The National Health Servicecould not possibly provide the personal handling need-

dividuals, not as part of a huge sausage machine," he

asid.
Concerspecialist DrithysLewis said the hospice
would have to be careful
who it accepted Many people spent too long in hospital, and the hospice could be used as a dumping ground. The NHS should

have no claim on it. The Bishop of Colchester. the Right Rev Roderick Coote, said the church pledged its support The hospice was a complement to the National Health Service, not a criticism of it.

He said once it was set up. funds for maintaining it would be available through cancer organisations. For Catholics.

Michael Stokes said " A hospice can also be a place of total healing. I don't necessarily mean getting up and going home again.

was once called "last rites," - the Catholic preparation for death, It is

done most of the work in rousing support in the area. Miss Irene Overton said support was coming from all sides of the health service doctors, nurses and aduninistrators.

# **TO BUILD** HOSPICE **FOR TOWN**

#### STAFFING

Mes Sarah Graham, of East Mersea, a former nurse who now works with Friends of the Elderly, said a hospice could remove the experience of death from people. She said it was important to understand and not fear it.

She was also warried about the hospics staffing. "The idea of a hospics

run by agency marses - 1 could happen - could mean t becomes a ghettar."

She suggested people put the energy into working as annietant last officers for the dying in hospitals. But she unid after the meeting that she still supported the idea of a hospice.

Winding up the meeting, Colchester Mayor Cyril Sergeant said " Colchester is a caring town. I think it is absulutely mervelloss that so many people turned was DO IT SHIRRIEF & EVENING."

It is something emiting in Colchester for many rears, he added. . The Garette Save - anWe studied about the development of the hospice movement because it was being discussed locally, and our president, Irene Overton, was very keen to be involved. We had an annual fundraising project and raised a record £1,360 that year, which just shows that the people who came to our fundraising events realised the importance of having a hospice and were very generous.

Club member Betty Lyes was out walking her dog one morning and met up with Peggy Spark from Altrusa and they said what a good idea it would be if the service organisations got together to raise funds. So ALRES – Altrusa, Lions, Rotary and Soroptimists – all worked together to fundraise.

Dianne Couch, Soroptimist International Colchester and District Club

Image: Essex County Standard, 10th July 1979



My particular job was public relations to try to get it off the ground. When I sat back and I looked at it I thought, well I have no product, no intelligence, and I'm trying to sell it to people! We spent hours talking, talking, talking, spreading the word about the hospice and getting it to be known. We were promoting something that didn't exist.

Back then, once they decided you were terminal, that was the end of you; you got crossed off the book, even though you hadn't died. There was a lot of pain that wasn't controlled. There was a need.

Allan Crabtree, public relations, council of management

**Pictured:** Ray Lester of Gainsborough Photographic Studios; Allan Crabtree and Peter Clements of St Helena Hospice; Bill Chatten of British Telecom (1984)



We only had £50,000 left in the bank. We had a meeting and the chairman went round to every member of the committee and asked if we should stop now.

Every day I went and picked up the biscuit tin where the donations were put. I opened up the tin. It was full of envelopes and there was one very big bulky envelope of cheques... £40,000. I couldn't believe my eyes. I phoned up Elizabeth straight away and I think we both shed a little tear. That was our answer; it meant we could carry on. It was miraculous. I'll never forget that feeling.

Mary Fairhead, appeal organiser, council of management

Pictured: Mary Fairhead (right) accepting a donation



I started on the fundraising side with Pat Gosling and we worked above the offices of Chris Holmes, who was chairman for many years. I can see it now, the room upstairs. It was full of donations, all sorts of things and masses of volunteers.

One day we found an envelope on the table with £500 in notes. We couldn't thank anyone and we couldn't really know if it was above board! The police couldn't throw any light on it, so we put it into the funds. It was just amazing.

You were just swept up into it. We were like a family.

Joy Higgins, PA and secretary to fundraiser Pat Gosling, administration

Pictured: Fundraising appeal office



It was quite remarkable because the local people and the local press supported the idea – that was kind of what the local press did in those days. Journalist Bill Tucker was a big driving force. He was a great stalwart.

We knew what happened to old folk and we knew there was a need for people at the end of life to be with as much comfort as could be mustered and just that feeling that if you are a civilised local community you need one. That's what pretty much drove everyone on and they all came together to make it happen.

Mike Ellis, deputy chief executive of Essex County Newspapers

Pictured: Myland Hospital nurses supporting the fundraising appeal, c1983



Hospice boost

THE Colchester St Helena Hospice appeal moved nearer its £1 million target yesterday.

A cheque for £3,000 was presented to Chris Holmes, chairman of the appeal,

by hospice fund-raisers from Lexden, the Cherrydale Weavers.

Most of the £3,000 was raised at a book sale and brings the total raised by the Weavers for the Hospice to nearly £7,000. We thought, we haven't got much money, but we have some time, why don't we see if we can *raise* a bit of money? We said we'd do it for a year and raise a £100 towards a bed. Well, the first year we made £1,500 so we've been hooked ever since. Everybody involved was treated as if they were important, which was lovely.

We put notices through front doors and we went back the next day to collect stuff to sell. People were very generous. Suddenly you had all these people saying, I can do that here you go. It was brilliant!

Dorothy Hewitt, Cherrydale Weavers, fundraising group of friends and neighbours

**Pictured:** Sue Dowrick, Jane Entwistle, Beryl Hutley, Pat Adams, hospice chairman Chris Holmes, Maureen Poulter, Rita Pincombe, Elizabeth Cook, Dorothy Hewitt



We started to look for premises and looked at several but they were all unsuitable and there wasn't any ground with them.

And then one day something quite extraordinary happened, fate stepped in. I was on a site visit in High Woods to do with my role as a councillor, and we had to walk from Mile End Road through a little lane to get there. I happened to look to my right and there was all this bramble and I could see a lovely old house amongst it.

I couldn't wait to get home to phone Joyce Brooks. I said I think I've found it! We completely fell in love with the old house.

Mary Fairhead, appeal organiser, council of management

**Pictured:** Dr Elizabeth Hall, Mary Fairhead, Allan Crabtree, Joyce Brooks and Gladys Teagle, Myland Hall, October 1981



My grandmother, Isabel Impey, was given Myland Hall by her father, Wilson Marriage, in 1910. I have many happy memories of skating on the pond, playing in the garden. It was a very happy house, a very busy house. They had cows, so in the war we always had milk and butter and cream, and there were mulberries and quinces in the garden; we were very lucky.

I was going there up until 1972 when there was a compulsory purchase on the house. The developer thought they were going to pull it down and build over it but then they found it was listed. So there was quite a big gap before the hospice bought it.

Angela d'Angibau

Pictured: Myland Hall, c1981



The Duchess of Norfolk was very supportive and she cut the first sod to mark the start of building work, which was a great day, that was fantastic. I loved it because we had a band there and they played 'heigh-ho heigh-ho, it's off to work we go' as she cut the turf. And there it was being built.

Dr Elizabeth Hall

**Pictured:** Christopher Holmes, chair of the council of management, with Anne, Duchess of Norfolk, at the ground breaking ceremony on 23<sup>rd</sup> November 1983



The Duchess of Norfolk came along before it was opened, when it was a building site. We had this room there that we were selling things to the people who came just to see it before it was ready. She spent quite a long time with us looking at all of the stuff we'd made and she bought two pencils decorated with Queen's Guard hats.

Pat Adams, Cherrydale Weavers

**Pictured:** Anne, Duchess of Norfolk, inspects the model of the future hospice building with Chris Holmes, chair of the council of management, 23<sup>rd</sup> November 1983



It was an old house in the middle of a field that had been used as temporary offices for the housing estate builders. I never knew anything about hospices; it was somewhere I'd heard that people go to die. I remember it was a bit poignant when we put the morgue in.

Sometimes there were things they hadn't got money for which needed to be done before we could do something else. A lot of the guys either hung on late at night or they worked at weekends to get A done so they could get on to B so things could move on. We were working for a good cause and we just all mucked in.

Colin Bruce, subcontracted carpenter for Huttons during the building project

Pictured: Myland Hall conversion, 1984



Pat Gosling said to me 'I think you should start the garden' and I thought where do I start? It was an absolute wilderness.

My husband came with machinery and lifted all the debris from the pond. It was nothing but debris, muddy water, and we were left with a huge area.

It really was volunteers that got everything going. Lovely farmers came and ploughed it, levelled it, seeded it. You just had to say you needed something and word spread around us. One weekend 16 firemen arrived, cleared the bushes and scrub around the pond, pumped it out and came back to refill it. The garden just became part of my life.

Margaret Farrow, council of management, led the team of volunteers in transforming the garden

Pictured: Margaret Farrow, hospice garden, 1985



My grandmother was very keen on the garden, but she was a Victorian, so she always seemed old, but her daughters who lived with her were very keen gardeners, Lillian and Alison.

Margaret Farrow knew I had family connections and asked if I'd like to do a border, and because it was a big family she thought I'd like a big border. I wrote to all my Impey relations and they donated money and then my local garden centre gave me each plant for £1. Then my husband and sons came over with all the equipment and we dug up the border.

Angela d'Angibau, volunteer gardener

Pictured: Angela and her son tending to the Impey border ahead of the Queen Mother's visit, April 1986



My first day here I spent picking up the front area as it had just been ploughed up and was full of big stones. It had been a farmer's yard, and the young farmers came to help stone pick.

Gradually we made flowerbeds. We were all amateurs, none of us had trained, we just all liked gardening.

There was a budgie cage in the courtyard before all of the building was done. One of the garden team, Pam, used to look after the budgies but people used to ring her up in the middle of the night and say there's a poorly budgie or something, and eventually it was done away with.

Cally Boutle, volunteer gardener

Pictured: Transforming the garden area by the pond, 1985



We had to recruit and train nurses and volunteers as virtually nobody had training in palliative care. We did some of this training in my dining room!

As we started to admit our first patients, we were still learning on the hoof but we were doing it together. I'd gone all over the country looking at different hospices, and wherever I went, people were telling me 'I feel so safe here'. After we opened I wondered how long it would be before somebody says that of us. It was within 48 hours, which was wonderful.

People thought it's fantastic and wanted to come to the hospice, but we were still fighting the concept that you go there to die.

Dr Elizabeth Hall, medical director

Pictured: Dr Elizabeth Hall outside the hospice, 1985



They were still finishing the place off. It was all very, very new. Walking through the door was like entering into a well-appointed hotel, which was confirmed even more when my wife and I were the first to use the guest suite overnight.

I remember being aware that Lisa would be the only patient there, wondering if she would be lonely. All the staff were so cheerful and helpful in making us feel at home. I remember Lisa the day before her last making a small recovery, being very happy and laughing and joking with the staff.

Brian Brenchley, father of 22 year old Lisa who was the first patient to be admitted on 20th May 1985

Pictured: Brian, Shirley, Lyn and Lisa Brenchley, 1984



I learned very quickly about listening to the patient; not to medicalise the illness and the diagnosis but to listen to them and their story. I was there on the very first day and I remember welcoming the very first patient.

I remember clearly the first death we had there too. It was a very young lady, younger than me, and I thought wow, the impact of that, she will never be my age.

Sue O'Neill, nurse

Pictured: Nursing team outside the hospice, May 1985



Most of us didn't know what we were doing at first because it was a new branch of nursing for us. I didn't know a thing about palliative care or about certain pain relief. I felt a bit out of it but I soon learned; I never stopped learning, every day something new.

Coming from a busy 40 bed hospital surgical ward to a 15 bedded unit, for the first month I was wondering what I was doing there because it was so quiet. But then it started; we soon got more patients in and we just got on with it. It was the best thing I ever did. It was lovely, like a family.

John Garbett, nurse

**Pictured:** Sister Terry Magee demonstrating the new bath hoist to John Garbett (centre) and some of the nursing team



We all came together to do training and it was everybody, including the people doing catering, cleaning and everything. I think we formed strong bonds because we were all learning together.

I can remember a lot of the patients still to this day because we had real characters and they were allowed to be themselves. There wasn't a regime. Families would ask 'what happens here?' and we'd say, well, you sort of do what you like really. Anybody who came to us, you couldn't predict what was going to happen; they were all individuals, that was what was so brilliant.

Jane Elliott, nurse

Pictured: Jane Elliott



I was one of four consultants' wives along with a high court judge's wife, who all came as volunteer nurses. We went along to a steering committee meeting and by the end of it we'd all signed up as volunteer nurses. It was my sort of nursing; don't give me machines, give me patients! Within three months I was back to work as a staff nurse.

We took it in turns to work at the new day centre and we had different groups of patients visiting for the day for things like baths and treatments, and the doctors would see them. Quite a lot of hands-on care.

Sarah Orr, nurse

Pictured: Joy Higgins, Sarah Orr, Elizabeth Hall, Nell Beresford-Jones and nurses



When I went for an interview with matron, she said all she wants is for the kitchen to be the hub of the place. If you're in your home, it's where most discussions take place, things always happen in the kitchen, and she wanted it to be like that there. I like to think that's what it was like.

There was always a choice. With the patients, if they particularly wanted something and we hadn't got it, we'd nip up the road to get it for them.

We had a lot of contact with the patients and we got to know them all, got to know their families.

Doreen Hill, cook

Pictured: Doreen Hill with kitchen volunteers



A nurse asked if I would mind coming to sit and speak with a German patient who had no family here and little English. It really brought it home to me just how much the staff cared for patients, realising the importance for them to be able to communicate in their last hours. I later also communicated with the family in Germany.

Lotte Sherman, kitchen and ward volunteer

I remember doing a jigsaw puzzle with a patient. We had the training on practical things like making beds and helping to lift patients, but I don't think until I had done a full shift that I actually realised how hands on we would be. We weren't there to just go round patting the bed and saying there there dear, don't worry; we were doing practical things.

Pat Nicholls, ward volunteer



Rain, lots of it, I remember. Everybody was in their dinner jackets standing at the edge of the tent in the garden, getting rained on. The band was inside because the rain was just dripping off the top of the tent all over us.

But it was a nice occasion because the hospice had just taken in the first patients and so it was almost like a thanksgiving service that it had finally opened after the years of getting it going.

Andrew Dickerson, trustee, sang in the University of Essex choir at the service of thanksgiving, 29<sup>th</sup> May 1985

Pictured: Hospice, May 1985



The Queen Mother was to take afternoon tea.

There was no dining room table suitable for her to take tea so I volunteered my dining room table, which was transported to the hospice, where the Queen Mother took tea on it. For a long time after we told our friends who came to dine with us that they were sitting at the table where the Queen Mother took tea!

Joy Higgins, administration

**Pictured:** The Queen Mother visiting to officially open St Helena Hospice on 11th April 1986



The Queen Mother stopped to talk to so many people, so I had to keep making fresh pots of tea because I thought I can't give her stewed tea! When she did eventually come to the table and Chris Holmes introduced me, I'd practised my little courtesy, and she said 'oh yes, a very important job'. Then I poured the tea.

Doreen Hill, cook

**Pictured:** Chris Holmes, chair of the council of management, watches on as Doreen Hill pours tea for the Queen Mother, 11th April 1986



When the Queen Mother visited, everybody was so excited; it was the beginning of the hospice and that was lovely. I remember going into one of the rooms with her and the patient had the television on and said to her 'I think we both like watching the races', and she said 'you get a better view on the telly!'

Requests by patients for extra painkillers went right down during that day. I think it was the joy of everybody meeting her.

Dr Elizabeth Hall, medical director

Pictured: Dr Elizabeth Hall with the Queen Mother and matron Jenny Wayte, 11th April 1986



We realised we were hardly going to raise the large sums required on our own. Spreading the word for others to help take up the challenge was the significant part of the job. In raising funds for the construction, we were also painfully aware it was not going to end with the opening and that we needed ongoing income apart from annual donations and bequests. And so we prepared to open our shop.

Peter Clements MBE, company secretary

I came into Colchester one day and I happened to see the Head Street shop not open but with a big notice on the door saying 'volunteers wanted'. It was opening the following week, so I thought, right, that's me. So I went in and started the first week they opened.

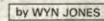
When I first started, my youngest son would come with me and he'd sit on the bench and direct operations; 'oh, I don't like that suit' or whatever it was! He was often there after school.

Tessa Proudfoot, shop volunteer

Pictured: Head Street shop, which opened in June 1987

### NHS sticks by decision to cut funds

# Hospice offers )S care





take All

Soon after the hospice opened, this whole situation was filling the news. I felt strongly that we had a role to play, as did many staff. After quite a bit of resistance it was agreed we could admit people with AIDS or who were HIV positive. It is hard to explain now what an achievement this was. However, we had hurdles to overcome in this atmosphere of fear and ignorance.

Dr Elizabeth Hall, medical director

When we first had a patient with HIV, it was very new and we all learned together. I think one of the big things was we learned from the patients. They taught us a huge amount. It was very interesting because of all the sociological things that were associated with HIV and AIDS and how the families felt about one of their family having an illness which was thought to be very non-acceptable.

Jane Elliott, nursing director

Image: Local newspaper reports, 1987



The day Princess Diana opened the centre was a memorable day. All my family were there, my children and my grandchildren. Princess Diana was very, very good with the patients. There were people sitting either side of her reading their poetry to her. She had a great gift with people.

I was delighted to see the day centre being used. The heart of the hospice is the people working there. The volunteers, the nurses; they have a very difficult job. Buildings are nothing else but inanimate, but the staff and volunteers are absolutely wonderful.

Robin Tomkins, who funded the day centre in memory of his wife, Joan

**Pictured:** Robin Tomkins (left) and Diana, Princess of Wales, at the official opening of the Joan Tomkins Centre, with Pearl Wheat, who presented a selection of poems about life and death written by patients and families, 26th April 1988



I was in the nursing station with all the girls around me and Princess Diana came in and made a beeline straight for me. She came up to me and said 'good morning', and I said good morning and she said 'how do you keep all this lot under control' and I said with great difficulty ma'am, with great difficulty.

John Garbett, nurse

**Pictured:** Diana, Princess of Wales, with John Garbett and nurses inside the hospice, 26th April 1988

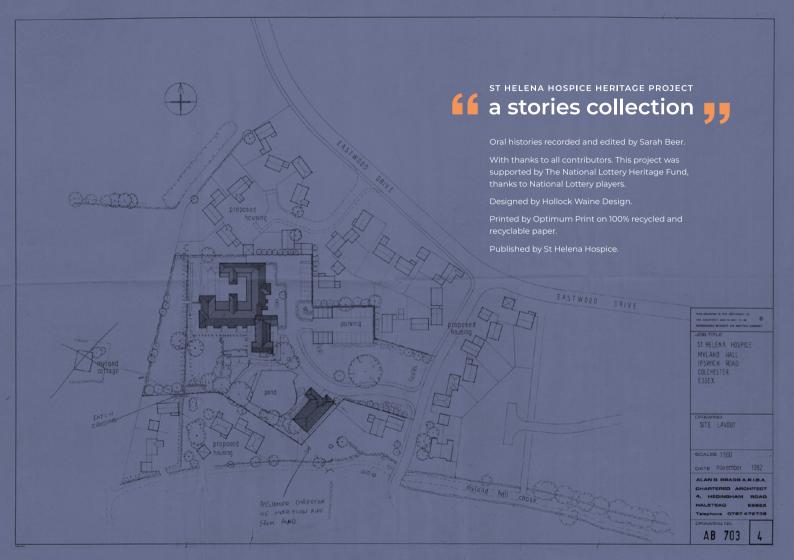


There was lots of excitement when Diana visited. She was lovely with the patients, so gentle. There was a gentleman who had been in the RAF and when she came in, he got off his bed and stood to attention, and she said 'oh, please don't; please make yourself comfortable'. She was absolutely lovely with the patients, really kind and gentle and very caring, sat on their beds and sat beside them and chatted.

Jane Elliott, nursing director

Pictured: Jane Elliott shows the hospice ward to Diana, Princess of Wales, 26th April 1988







A collection of oral histories and photographs of some of the people who volunteered their time, skills and passion to bring hospice care to Colchester and Tendring.













### Appendix D

**Life Stories Collection booklet** 

ST HELENA HOSPICE

## 66 life stories

With heartfelt thanks to all contributors for sharing their Life Stories.

www.sthelena.org.uk/lifestories

Photography captured at the time of recording the oral histories in people's homes across north east Essex and at St Helena Hospice.

The Life Stories project was funded by the Essex County Council Arts & Cultural Fund





ST HELENA HOSPICE

# 66 life stories









www.sthelena.org.uk/lifestories



**life stories** gg captures the oral histories of some of the people supported by St Helena Hospice across north east Essex, thanks to funding from the Essex County Council Arts & Cultural Fund.

Stories and memories recorded on audio and video celebrate people beyond their diagnosis, as they reflect on a whole life lived and what matters to them as they face end of life.



My mother came from Malta and so did I and my brother. My father was a soldier in the war and we came to England after the Armistice. Unfortunately, my mother died in childbirth, and he found it very hard to look after his two boys so we was going to be put into the orphanage. Well, you can imagine the orphanage in the 1950s, like Charles Dickens. Anyway, my aunt and uncle said 'move up here with us and we'll look after the boys'. Well, moving up here was moving into Paddington, which was rat-infested Victorian houses, but it was a roof over our heads. It was somewhere for us two boys to be cared for.

The years went by and on my 16th birthday, my father came up to my aunt's house where I lived and he said to me 'look out there, son, what do you think of that?' And there was an old ex-army Norton 500 and she was the bee's knees. My father jumped on, I got on behind him and he took me into the countryside, and that is where I began my training to be a motorcyclist.

We used to go out for rides down to Brighton. I've even rode up the Devil's Dyke on a solo bike bumping one side to the other! It's great, it's freedom, because that was part of them days after the war; you got what you could or you begged, borrowed or stole it.

### Arthur Peacock



I was born in London right opposite the ladies' prison, Holloway. We had a couple of rooms at the top of the house and every time you wanted to go to the toilet, you went all the way to the bottom of the house and then you had to go all the way back up to the top of the house.

It was after the war, when they were beginning to repair places, that we actually had water put on because we had to have two buckets; one for the dirty water and one for the clean water. Down all the way to the bathroom with the dirty water to flush away, clean water in the other, then carried it all the way upstairs again!

My mum and dad were quite poor. They'd had a daughter before my sister was born but sadly, she died at five years old when measles was on the rampage.

The main part of our childhood was the summer holiday because a good thing I looked forward to was going down to my aunt's in the Cotswolds. Oh, we had some lovely times down there; paddling in the brook, doing fishing in the brook, only little tiny tiddlers.

My uncle was the baker down there and they used to mill the corn and bake the bread and what have you. We just used to wait and wait and wait just for that day to come when we got on the train and off we went.

### **Beryl Smith**



I have been active the majority of my life. I've enjoyed walking. I climbed Scafell Pike with my two daughters. The year before with my younger daughter and my brother, did Snowdon. I've enjoyed walking in the Lake District and I lived in Yorkshire for a while so did quite a bit of walking over there, so yeah, been an active person.

My daughter, Anna, was due to be married and the hospice doctors said the best option was for the marriage blessing to be brought forward. I really wanted to say my little bit to my daughter and son-in-law. I am in a wheelchair now, so it was a great joy for me that they were able to support me as I stood and read what I wanted to read and that they can then keep those words.

What was the greatest, greatest blessing for me was, I have four grown up children and two granddaughters and they all came together. We had the joy of the grandchildren running around and playing. Out of sadness, joy can come. We had the celebration within the grounds of the hospice. A wonderful place to have it, just magical, absolutely magical.

That meant a lot to me and to Anna as well. She was happy to see me looking happy and content and just being a mother of the bride and having a little blubber as mother of the bride. That was a very, very special day.

### **Catherine Loring**



We were a completely normal family. I had a job in London, I'd commute, loved it. I saw my friends at weekends, went out, made the most of life. We were really good at just living in the moment and enjoying life because I've always been ill. So there's always been times where, you know, I'd have a birthday party and I wouldn't even make it to the happy birthday blowing out the candles because I was so poorly. So we enjoyed life as much as we could.

I love Christmas! Family time. Our Christmas Day looks like me, my brother, my mum and my step dad all in Christmas pyjamas. We spend the whole day together, do presents in the morning, the Christmas fry up, and then Mum opens the wine and starts the Christmas dinner. And then we watch Christmas films and just spend time together.

All I care about is that my family is OK and they're looked after so everyone's able just to get on and just be family and focus on the family stuff, which is why Christmas is so important.

I'm a really good gift giver. I pride myself on my gift giving and I actually prefer seeing other people open my gifts to opening my own presents. We have to wait to decorate our tree because Mum said that I'm not allowed to decorate in November, even though I want to, so as soon as it's the 1st December, I'm like, it's Christmas!

### Daisy Murfin



I've always been happy, always had a happy face.

I've lived in Harwich all my life. I used to love going in the water, I love a swim, I used to go in at 7 o'clock in the morning until 12 o'clock at night. My missus used to moan like hell cos she couldn't swim! Used to be full of people on the beaches, all up there on the promenade. People used to open their doors, give you a cup of tea.

I had a job at the coal yard loading up all the coal ships what come in. I left the boats and had to go in the army. When I went up to Ipswich I was passed by six army doctors; it was just like being on the pictures, all these clinical lads saying bend down, jump or whatever. Said 'you're all fit, you'll hear in a week'. I never told me mum and when the letter come I got in, I just left a note on the table saying to me mum *I'm gone away for a little while, I'll get in touch with ya*.

Got to Wrexham, we had to sleep in tents, oh that was cold. I first joined there with a load of blokes, we trained really well, went over all the assault courses, crawling around in the mud, we used to get saturated!

They said to me 'where's Harwich?' and I said 'in Essex somewhere'. They didn't know where Harwich was!

### **Ernest Wink**



Because I love the sea, my son took me to Walton on the Naze and there's a Hell's Angels biker café there. I used to ride in my youth because my friend's boyfriend was in a group of Angels and they would let me ride on the back of their bikes. I've always loved it and I've always remembered it.

My son went into the café and he said 'the lady in the wheelchair out there really wants to have a ride'. This man, Dave the Donk he was called, had a trike with a double saddle, said he would take me. So I got out of my wheelchair, walked over to the bike, got my dress up like that and just climbed on.

He took me all along the coast road sounding his horn and waving. Then he took me around the town and then back along the front. It was the most wonderful experience I ever had in a long, long time, many years. I was in my element. He was saying 'tell me if I'm going too fast' and I'm like faster, faster! I am a daredevil. I love the speed.

That was one of my last wishes before I die. And that happened on my 70th birthday. I'm still feeling it in my heart now. It's in my soul, the memories I've got.

Experience things. Look at nature. Look at what is around you in this world. We're not here for long, so experience the world.

### Jacqueline Grogan



My life has been a pretty charmed life and I've been very lucky. I lived for the first portion of my life with my mum and dad in Essex in a lovely house, big garden.

All I craved as a youngster was to ride horses, much to my parents' disapproval because I think they thought that sounded quite expensive, and I think they thought that sounded dangerous. But eventually they gave in and I learnt to horse ride with friends at the age of about 7.

At the age of 18, when it was finally deemed that I could afford one myself and be able to look after it myself, I bought one with my first bonus money. He was very beautiful and adorable and looked after me very well. He was with me for 25 years or more, a long, long time, in fact, longer than my mum because she passed away when she was 57. Every spare bit of money went in a pot towards the horse, I had a lovely time.

My husband and I married just after my 40th birthday, a small affair in a pretty little cliff top location in Fiji. My husband convinced me to have a big celebration when we came home for the family. I was kind of thinking *ohh sounds like a lot of work* but I'm really glad we did it now because it was just before Covid and it was really nice to have that big celebration and have everybody there to share it with us.

### Julie Warmington



Probably been married 42 years. We just went off, left a note for my secretary on the desk saying 'just going off to get married'. Lunchtime, well the Registry office was only 100 yards away.

It was when I was at a photographic company on cruise ships for passengers to have their photos taken, so a lot of travelling involved. I started off being a photographer, I ended up being an IT manager at Bradwell Power Station, so a bit of a difference.

We always had great holidays. We had very well-travelled children, even though the younger one would say 'why can't we go camping like our friends, why do we have to go on a cruise ship?' We have two girls, four grandchildren, it is perfect.

Life is short, make the most of it. We're born, we live, we die. I'm here to enjoy myself.

### Kit Thompson



Creativity, I've always been that type of person with my photography and on the arts side of things. It's like this table; sand it down and tile it and make something beautiful.

I am a qualified salsa instructor; 18 years I've been doing that. I'd go to Blackpool, all over the country. When I was younger I did ballet as well.

Because of the dancing and photography, I've always been confident, so when it comes to living, I feel that I just want to keep going because of the way I am as a person. It's like teaching someone to dance; you've got 12 weeks to learn, I'm not going to stop in 6 weeks, I'm going to keep going until you can dance and then you're going to say thank you for what you've done for me. Makes me feel good.

I've got carpentry and bricklaying too. My dad's motto was 'skills pay the bills', so I say learn as much as you can through life.

My dancing keeps me young; my whole personality keeps me young. I like to always look nice. I've gone to weddings and the groom's gone 'huh, typical! I knew you would turn up in a better suit than me' and I say *can't help myself*, *sorry mate!* I have a sense of humour; I tend to wake up and just like making people laugh.

### Malcolm Green



Born and bred in North London. Had a pub in Belgrave Square behind Harrods and after that a pub in North Finchley.

Postman for 30 years, loved being outside. Favourite food, jam on toast. Did have a Harley, love the speed.

My mum's sister was living in Frinton and they were boat mad and built their own boats. My parents would take me out on the boat. We had lots of fun times doing all kinds of things; sailing, crabbing, fishing, even just rowing round the backwaters was fun.

Sailing... sailing makes me happy. I love the feeling when you get a gust of wind and the boat reacts really well, it's quite surprising how quick they go. It's the feeling you get, just the wind pushing you along. I like the freedom, you can go to places no one else can go.

The peace and quiet and being lost in the world is lovely.

### Mark Van Baars



I was born in Colchester. I think I was born in the maternity hospital. I'm the oldest of seven, big families in them days. Went to school in Greenstead Road, that was in the '60s, that were good days, surprising what I got up to! It was all farmland up here then.

Lived here in this house since I got married, 55 years. I lived for a while in a maisonette then moved to here because this lady wanted a change. We came and had a look and she looked at ours. We done the change through the council and after a few years, Margaret Thatcher did this Right to Buy and I bought this house.

I worked all my life, virtually, cutting grass for the council. I was outside working all my life. a lot healthier. I retired when I was 70.

I've had a good life. I've had a good wife and everything, and kids. What makes me happy is my wife and people what come round to see me because I feel a lot better chatting to them than being on my own.

The 1960s were good. The '66 World Cup was good. Used to like life, socialising and dancing, rock n roll. Used to sing on a lot of karaokes, used to love them. I was a football man, played football until I was 45.

### Neil Harden



I was born in Yorkshire, a family of three boys, I was the youngest. It was a very happy family. After school, all of us three boys won scholarships. I went straight to university, I read geography, I did well and then I volunteered with voluntary services overseas and I was the first VSO to go to Sudan. I came back in 1965 and those friendships have endured.

When I was in Hull, they had wonderful trawlers that went out to catch mainly cod. I let it be known I wouldn't mind a trip and one summer I went for three weeks up to Bear Island in the Arctic and we caught 300 10-stone kits of fish. It was absolutely amazing. We caught quite a big halibut and they gave me it at the end of the trip. I took it home and we had it for our Christmas.

That was wonderful and it made me even more love the idea of the sea. I said I think we ought to go look at some boats and we drove from London to the coast, Tollesbury, and bought a 23 foot yacht then and there. I'd been saving money ever since I started work and I said to Julia 'we put these things away for a rainy day, well as far as I'm concerned, it's been pouring!'

I hadn't a clue, I did a correspondence course and the boys helped. Well, we had the most wonderful time in that boat. We actually got it to Dunkirk.

### **Rod Usher**



Born during the depression, hard times for my family, straight into the war. My dad was off and didn't really see him for years. I remember during the war we went to Wales for a short period when dad was stationed there but we weren't evacuated.

We lived on the edge of London and we caught the edge of the Blitz. Several times all doors and windows blown out, bombs dropped, fortunately not too close to our house. I remember hearing and seeing a doodlebug, hear the buzz of the engine, then it cut out and dropped somewhere just at random.

As children we used to collect shrapnel. After a raid you could go outside, walk along the street and there'd be lumps of red-hot shrapnel lying around from shells. We had an Anderson shelter in the back garden, just corrugated, and you'd go down and sleep in the shelter.

Hard times followed the war, even up until the '50s really with the food rationing, clothes rationing, it was hard. We weren't the worst off, we were lucky.

National Service in the '50s, I was stationed in Germany during the cold war. Spitfires were more or less phased out by the time I was in the RAF but I've always had an interest in aircraft right from my younger days. I was a member of the Boxted Airfield Museum, and my wife, Beryl, and I joined the Boxted Airfield Historical Group.

Happiest moment was getting married and then having a family. Family is everything.

### Ron Tickner



I saw Donny Osmond on telly in the early '70s, I didn't know who The Osmonds were and my love for Donny started then I think.

It was in 1975 my sister took me on a surprise trip to a concert, to The Osmonds, somewhere in London. I'd never been to a concert before. I was like, I'm in the same room as Donny Osmond! It was amazing.

I'll never forget during one of his songs I just sat down crying and as I looked up, he raised his hand and I thought *he can see me, he's seen me.* Donny Osmond's seen me!

And then The Osmonds went off the picture for a little while and in the early '80s they done some comeback tours. Whenever he was over in the country, even if I couldn't get tickets to the concert, I'd go and stand outside the stage door. At one, we went round by the stage door and there's a little pub over the road, so we're sitting there and then Jeanie goes to me 'over there, look, a commotion'. He just walked down the street. So I went over, pushed some woman out of the way and then walked along with him holding his arm.

I'm perfectly calm until I see him and I am all of a sudden that mad woman!

### Rosie Curtis



I'm very much a home bug. I like my home, I like my garden, I like sharing it with friends and family.

I left school when I was 16 because I didn't think I was academically equipped to do anything else. I had dreams of being a teacher, a researcher, but it was just a dream that I never thought would ever happen. But thankfully, Rachel gave me the opportunity to take some time out from work and go and do an undergraduate degree. And I loved it so much and did so well that I stayed on to do an MA. And I loved that so much and did so well, I got a scholarship to work on a PhD.

Some of my happiest memories, well, the happiest memories, have been associated with the sea. We travel a lot to Scotland in our camper van where you can literally camp on a beach in certain places. What is it about it? It's about association. It's about the colour, it's about the movement. There's something very refreshing about the sea. Something quite healing about it.

I love losing myself in a book and it's particularly wonderful with audio books because you can lose yourself whilst doing something like painting or gardening, two of the things that I've grown to love doing. So yes, listening to a book whilst gardening or painting, they're my favourite kind of spaces to be in when I'm not with Rachel.

### Viv Ashley



### Appendix E

Heritage artwork panels



www.sthelena.org.uk/heritage







### 66 St Helena Hospice heritage stories "> 17

St Helena Hospice welcomed its first patient, 22 year old Lisa Brenchley, on 20<sup>th</sup> May 1985.

The vision started in 1979 and took six years of planning, fundraising and construction before the doors to the hospice building opened for the first time.

"St Helena Hospice heritage stories" is a celebration of the people who volunteered their time, skills and passion to bring hospice care to our community.







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## MEETING BACKS PLAN

### STUART BUCKMAN

A PACKED public meeting has pledged support for a hospice for the terminally ill in the Colchester area.

About 130 people, including many from the medical world, launched the scheme by setting up a 15-strong steering committee. they could not be helped.

But a note of warning was sounded from the floor. A former nurse warned that the hospice could become a ghetto.

Former Colchester Mayor Mrs Joyce Brooks opened the meeting by saying hospital resources were stretched to the limit.

### FAMILIES

She introduced Sister Deirdre Allen, of Myland Hospital, who has studied hospices and worked at St Anne's hospice in Manchester, and explained the role of a hospice in the care of the terminally ill.

"They are about caring for people and their families — and being cared for in pleasant surroundings by people who think that is the work they want to do," she said.

Raising the money would be a long job. She hoped people would keep up their interest.

Consultant physician Dr Peter Kennedy said: "Death is one of the most important events in our lifetimes, and there are many people these days for whom the last few days are unpleasant, lonely, humiliating and full of pain. And this can be avoided."

### MACHINE

He said many people could not rely on family support and help. Debilitating illness could hit anybody, and there was no reason

they could not be helped. The National Health Service could not possibly provide the personal handling need-

ed.
"They are people who have to be cared for as individuals, not as part of a huge sausage machine," he

Cancer specialist Dr Rhys-Lewis said the hospice would have to be careful who it accepted. Many people spent too long in hospital, and the hospice could be used as a dumping ground. The NHS should have no claim on it.

have no claim on it.

The Bishop of Colchester, the Right Rev Roderick Coote, said the church pledged its support. The hospice was a complement to the National Health Service, not a criticism of it.

He said once it was set up, funds for maintaining it would be available through cancer organisations.

For Catholics, Mr Michael Stokes said: "A hospice can also be a place of total healing. I don't necessarily mean getting up and going home again."

necessarily mean getting up and going home again."

He compared it to what was once called "last rites," — the Catholic preparation for death. It is now a prayer of healing.

The Soroptimists have done most of the work in rousing support in the area. Miss Irene Overton said support was coming from all sides of the health service — doctors, nurses and administrators.

### STAFFING

Mrs Sarah Graham, of East Mersea, a former nurse who now works with Friends of the Elderly, said a hospice could remove the experience of death from people. She said it was important to understand and not fear it.

She was also worried

about the hospice staffing.
"The idea of a hospice
run by agency nurses — it
could happen — could mean
it becomes a ghetto."

She suggested people put the energy into working as assistant last officers for the dying in hospitals. But she said after the meeting that she still supported the idea of a hospice.

Winding up the meeting, Colchester Mayor Cyril Sargeant said: "Colchester is a caring town. I think it is absolutely marvellous that so many people turned out on a summer's evening."

"It is something wanting

in Colchester for many years," he added.

• The Gazette Says — opposite page.

# TO BUILD HOSPICE FOR TOWN

We studied about the development of the hospice movement because it was being discussed locally, and our president, Irene Overton, was very keen to be involved in starting one in the area. We raised a record £1,360 that year which just shows that the people who came to our fundraising events realised the importance of having a hospice and were very generous

> Dianne Couch, Soroptimist International; Colchester and District Club

Image: Essex County Standard, 10th July 1979

REPORT OF A MEETING HELD IN THE GRAND JURY ROOM, TOWN HALL, COLCHESTER, ON FRIDAY, 6th JULY, 1979 TO CONSIDER THE SETTING UP OF A HOPICE FOR THE TERMINALLY ILL TO SERVE THE COLCHESTER HEALTH DISTRICT.

Present: The Bishop of Colchester Father Michael Stokes Doctor Kennedy Doctor Rhys Lewis Miss Dierdre Allen Miss Irene Overton

and some 140 members of the public

The Bishop opened the meeting with a prayer.

Councillor Mrs. Joyce Brooks, in the chair, welcomed all those present and said their support was indicative of the need for a Hospice in this area, particularly as our existing Hospitals were stretched to the limit. She said the person behind calling this meeting was Sister Dierdre Allen who then addressed the meeting.

The Chairman then called on Doctor Kennedy, Doctor Rhys Lewis, The Bishop of Colchester and Father Michael Stokes who all addressed the meeting. (attached press cutting gives extracts from their

Miss I. Overton, President Colchester Soroptimists, then outlined the part her organisation wished to play. During her year of office money raised would enable the expenses of investigations into the setting up of a Hospice to be carried out and until the organisation had been registered as a Charity, they would hold any monies and this would then be handed over at the appropriate time.

At this point His Worship the Mayor of Colchester, Cllr. Cyril Sargeant and the Mayoress arrived and Mrs. Brooks welcomed them and thanked the Mayor for allowing us the use of the Grand Jury Room for the meeting.

The Chairman then put to the meeting the following resolution -

'That the project to establish a Hospice for the Colchester Health District should be undertaken and that a Steering Committee and Fund Raising Committee should be established to achieve this'.

This was carried unanimously.

The Chairman then suggested a Steering Committee should be set up and, at the wish of the meeting, it was agreed to do it then and that the Fund Raising Committee be set up at a later date when the time was appropriate to officially launch the appeal. It was stressed by Mr. C. Minter that it was important that the fund raising was done in a very professional way (on the lines of the Nursing Home appeal) and he was prepared to advise in any way possible and would endeavour to enlist the services of a colleague to act as Treasurer.

It was agreed that the Steering Committee should be represented by -Consultants: G.P's: Community Nursing: R.C.N.: Social Worker: E.A.H.A.: Councillor: C. of E.: R.C. Church: Society of Friends: Free Church: C.C.V.S. and the following were duly elected to serve :-

Dr. Rhys-Lewis: Dr. Kennedy: The Bishop of Colchester: Father Michael Stokes: Miss D. Allen: Miss G. Gallifant (Community) Mrs. B. Mears (R.C.N): Doctor Dawkins (C.C.V.S.O): Mr. B. Maguire (Dist.N.O. E.A.H.A): Mr. M. O'Keefe (E.A.H.A): Miss I. Overton and Mrs. Arkell (Social Workers): Miss Tegall (Society of Friends): : Mrs. Joyce Brooks.

The Chairman then said it was important we had an impressive list of persons for Patrons and asked The Mayor if he would accept and be our first Patron. The Mayor then said he would be very pleased to do so. He also said that the number of people who had turned up at the meeting was indicative of Colchester being a caring town and he would give any support he was able to the project.

The following names were suggested to be approached -

The Lord and Lady Alport Mr. Antony Buck M.P. Mr. Julian Ridsdale M.P. The High Sheriff, Mr. B. Harrison The Bishop of Brentwood Lord Seebohm Mrs. M. Whitehouse

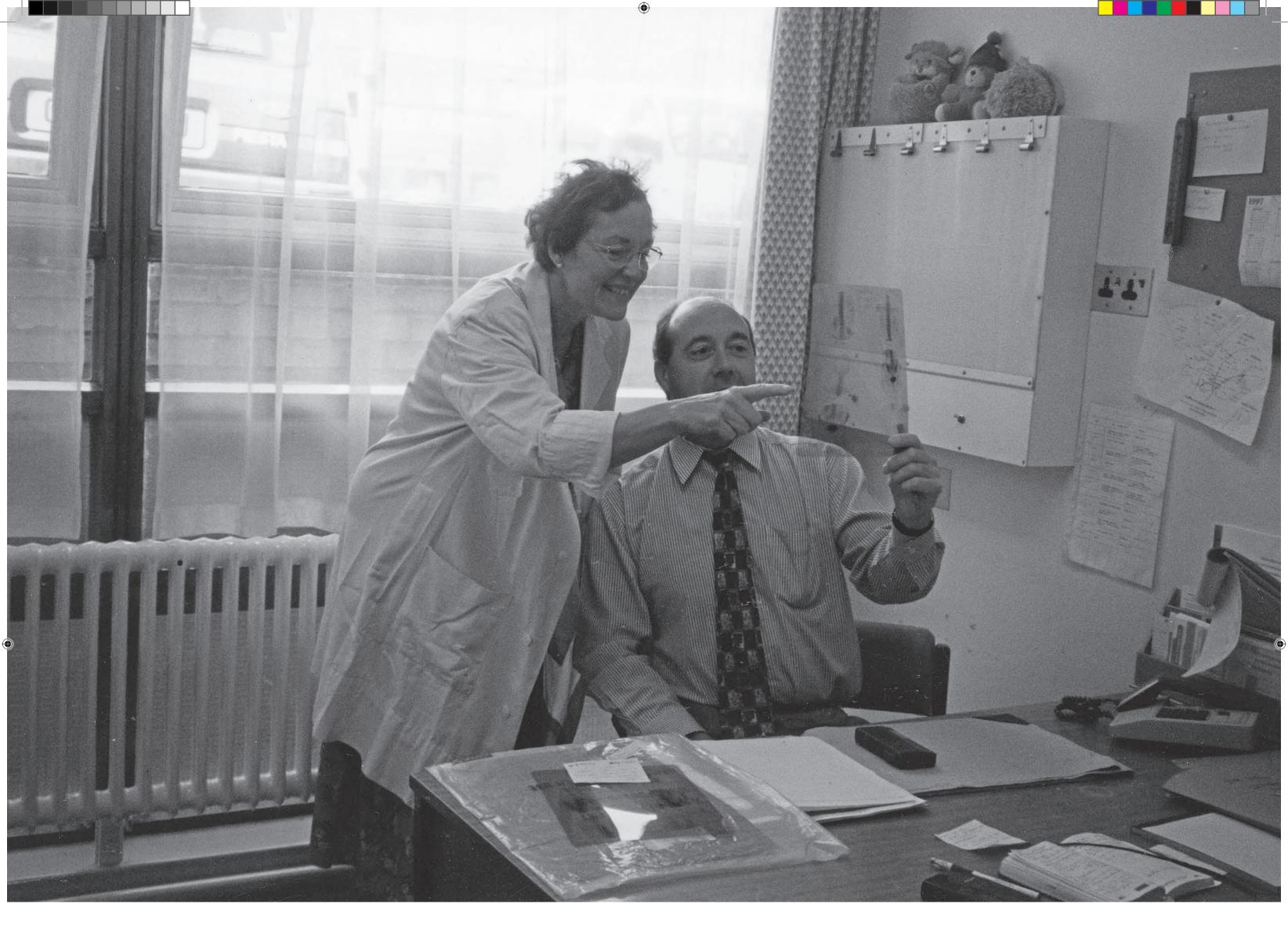
All members present were asked to complete a form showing how they were able to support the project.

Father Michael Stokes then closed the meeting with a prayer.

A collection raised the sum of £80.

The outcome for patients with lung cancer on the chest ward was pretty grim and they needed to be looked after in their terminal days. It became apparent to sister Deirdre Allen that we needed more than our few beds and we were amassing more and more patients as time went by. Deirdre went off on a course and came back convinced we needed a hospice.

Dr Peter Kennedy, consultant working with Deirdre Allen at Myland Hospital Image: Report of a meeting held on Friday 6<sup>th</sup> July 1979



St Helena Hospice came about because several people could see that we could be looking after people who we then called 'terminally ill', much better. With better understanding and symptom control people could be helped to face their future honestly. There is, as Dame Cicely Saunders said, an emphasis on helping people to *live* until they die.

Dr Elizabeth Hall, chair of the steering committee

Pictured: Dr Elizabeth Hall and Dr Phil Murray, oncology department, Essex County Hospital



Every day I went and picked up the biscuit tin where the donations were put. I opened up the tin. It was full of envelopes and there was one very big bulky envelope of cheques... £40,000. I couldn't believe my eyes. I think we both shed a tear. That was our answer; it meant we could carry on. It was miraculous. I'll never forget that feeling.

Mary Fairhead, appeal organiser, council of management

Pictured: Myland Hospital nurses supporting the fundraising appeal, c1983



My particular job was public relations to try to get it off the ground. When I sat back and I looked at it I thought, well I have no product, no intelligence, and I'm trying to sell it to people! We spent hours talking, talking, talking, spreading the word about the hospice and getting it to be known.

Allan Crabtree, public relations, council of management

Pictured: Ray Lester of Gainsborough Photographic Studios; Allan Crabtree and Peter Clements of the hospice; Bill Chatten of British Telecom, January 1984



Hospice boost

THE Colchester St Helena Hospice appeal moved nearer its £1 million target yesterday.

A cheque for £3,000 was presented to Chris Holmes, chairman of the appeal,

by hospice fund-raisers from Lexden, the Cherrydale Weavers.

Most of the £3,000 was raised at a book sale and brings the total raised by the Weavers for the Hospice to nearly £7,000.

We thought, we haven't got much money, but we have some time, why don't we see if we can *raise* a bit of money? We said we'd do it for a year and raise £100 towards a bed. Well, the first year we made £1,500 so we've been hooked ever since. Everybody involved was treated as if they were important, which was lovely.

Dorothy Hewitt, Cherrydale Weavers, a group of friends fundraising since 1981

Pictured: Sue Dowrick, Jane Entwistle, Beryl Hutley, Pat Adams, hospice chairman Chris Holmes, Maureen Poulter, Rita Pincombe, Elizabeth Cook, Dorothy Hewitt



We knew there was a need for people at the end of life to be with as much comfort as could be mustered. That's what pretty much drove everyone on and they all came together to make it happen. It was quite remarkable because the local people and the local press supported the idea. Journalist Bill Tucker was a big driving force. He was a great stalwart.

Mike Ellis, Essex County Newspapers

Pictured: Local newspaper cuttings 1979-1984

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I can see it now, the room upstairs. It was full of donations, all sorts of things and masses of volunteers. One day we found an envelope on the table with £500 in notes. We couldn't thank anyone and we couldn't really know if it was above board! It was just amazing. You were just swept up into it really. We were like a family.

Joy Higgins, PA and secretary to Pat Gosling, administration Pictured: Fundraising appeal office



One day something quite extraordinary happened, fate stepped in. Walking through a little lane, I happened to look to my right and there was all this bramble and I could see a lovely old house amongst it. I couldn't wait to get home to phone Joyce Brooks. I said I think I've found it! We completely fell in love with the old house.

Mary Fairhead, council of management

Pictured: Dr Elizabeth Hall, Mary Fairhead, Allan Crabtree, Joyce Brooks and Gladys Teagle, Myland Hall, October 1981



My grandmother Isabel Impey was given Myland Hall by her father in 1910.

I have many happy memories of skating on the pond, playing in the garden.

It was a very happy house, a very busy house. They had cows, so in the war we always had milk and butter and cream, and there were mulberries and quinces in the garden; we were very lucky.

Angela d'Angibau maintains the Impey border along the driveway in memory of her family connection to Myland Hall Pictured: Myland Hall, c1970



The Duchess of Norfolk came along before it was opened, when it was a building site. We had this room there that we were selling things to the people who came just to see it before it was ready. She spent quite a long time with us looking at all of the stuff we'd made and she bought two pencils decorated with Queen's Guard hats.

Pat Adams, Cherrydale Weavers, a group of friends fundraising since 1981

Pictured: Anne, Duchess of Norfolk, inspects the model of the future hospice building with Chris Holmes, chair of the council of management, 23<sup>rd</sup> November 1983



The Duchess of Norfolk was very supportive and she cut the first sod to mark the start of building work, which was a great day, that was fantastic. I loved it because we had a band there and they played 'heigh-ho heigh-ho, it's off to work we go' as she cut the turf. And there it was being built.

Dr Elizabeth Hall

Pictured: Chris Holmes, chair of the council of management, with Anne, Duchess of Norfolk, at the ground breaking ceremony on 23<sup>rd</sup> November 1983



Sometimes there were things that they hadn't got money for which needed to be done before we could do something else. A lot of the guys either hung on late at night or they worked at weekends to get A done so they could get on to B so things could move on. We were working for a good cause and we just all mucked in.

Colin Bruce, subcontracted carpenter for Huttons during the building project Pictured: Myland Hall conversion, 1984



I thought where do I start? It was an absolute wilderness. It really was volunteers that got everything going. Lovely farmers came and ploughed it, levelled it, seeded it. You just had to say you needed something and word spread around us. One weekend 16 firemen arrived, cleared the bushes and scrub around the pond, pumped it out and came back to refill it. The garden just became part of my life.

> Margaret Farrow, council of management and led the team of volunteers in transforming the garden

Pictured: Margaret Farrow, hospice garden, 1985



**66** I'd gone all over the country looking at different hospices, and wherever I went, people were telling me 'I feel so safe here'. After we opened I wondered how long it would be before somebody says that of us. It was within 48 hours, which was wonderful. People thought it's fantastic and wanted to come to the hospice, but we were still fighting the concept\_ that you go there to die.

> Dr Elizabeth Hall, medical director Pictured: Dr Elizabeth Hall outside the hospice, 1985



I learned very quickly about listening to the patient; not to medicalise the illness and the diagnosis but to listen to them and their story. I was there on the very first day and I remember welcoming the very first patient. I remember clearly the first death we had there too. It was a very young lady, younger than me and I thought wow, the impact of that, she will never be my age.

Sue O'Neill, nurse

Pictured: Nursing team, May 1985



They were still finishing the place off. It was all very, very new. I remember being aware that she would be the only patient there, wondering if she would be lonely. All the staff were so cheerful and helpful in making us feel at home. I remember Lisa the day before her last making a small recovery, being very happy and laughing and joking with the staff.

Brian Brenchley, dad of 22 year old Lisa who was the first patient to be admitted on 20<sup>th</sup> May 1985 Pictured: Room inside the hospice, May 1985



I was one of four consultants' wives along with a high court judge's wife, who all came as volunteer nurses. We went along to a steering committee meeting and by the end of it we'd all signed up as volunteer nurses. It was my sort of nursing; don't give me machines, give me patients! Within three months I was back to work as a staff nurse.

Sarah Orr, nurse

Pictured: Joy Higgins, Sarah Orr, Elizabeth Hall, Nell Beresford-Jones and nurses



I remember doing a jigsaw puzzle with a patient. We had the training on practical things like making beds and helping to lift patients, but I don't think until I had done a full shift that I actually realised how hands on we would be. We weren't there to just go round patting the bed and saying there there dear, don't worry; we were doing practical things.

Pat Nicholls, ward volunteer Pictured: nurse with patient



A nurse asked if I would mind coming to sit and speak with a German patient who had no family here and little English. It really brought it home to me just how much the staff cared for patients, realising the importance for them to be able to communicate in their last hours. I later also communicated with the family in Germany.

Lotte Sherman, kitchen and ward volunteer

Pictured: Kitchen volunteers with cook Doreen Hill



Most of us didn't know what we were doing at first because it was a new branch of nursing for us. I didn't know a thing about palliative care or about certain pain relief. I felt a bit out of it but I soon learned; I never stopped learning, every day something new. It was the best thing I ever did. It was lovely, like a family.

John Garbett, nurse

Pictured: John Garbett (bed) and some of the nursing team



There was a compulsory purchase on the house in 1972. The developer thought they were going to pull it down and build over it but found it was listed, so there was quite a big gap before the hospice bought it. Margaret Farrow knew I had family connections and asked if I'd like to do a border. I wrote to all my Impey relations and they donated money and my local garden centre gave me each plant for £1.

Angela d'Angibau, volunteer gardener

Pictured: Angela and her son tending to the Impey border ahead of the Queen Mother's visit, April 1986



The Queen Mother stopped to talk to so many people, so I had to keep making fresh pots of tea because I thought I can't give her stewed tea! When she did eventually come to the table and Chris Holmes introduced me, I'd practised my little courtesy, and she said 'oh yes, a very important job'. Then I poured the tea.

Doreen Hill, cook

Pictured: Chris Holmes, chair of the council of management, watches on as Doreen Hill pours tea for the Queen Mother, 11<sup>th</sup> April 1985



We realised we were hardly going to raise the large sums required on our own. Spreading the word for others to help take up the challenge was the significant part of the job. In raising funds for the construction, we were also painfully aware it was not going to end with the opening and that we needed ongoing income apart from annual donations and bequests.

Peter Clements MBE, company secretary, council of management Pictured: Head Street shop in Colchester which opened in June 1987



I can remember a lot of the patients still to this day because we had real characters and they were allowed to be themselves.
There wasn't a regime.
Families would ask 'what happens here?' and we'd say, well, you sort of do what you like really.
Anybody who came to us, you couldn't predict what was going to happen; they were all individuals, that was what was so brilliant.

Jane Elliott, nurse
Pictured: Jane Elliott

Hospice AIDS offer protest

Employees, said: "I feel this statement from the

AIDS plan at hospice criticised

ying it is prepared to admit

"Many Essex people gave generously to the this hospice with the now

already under-financed

Mr Dallisson has said the hospice is open to any terminally ill patient who

"Therefore if, in our professional judgment,

the challenge hospices faced with AIDS patients.

But St Helena's medical adviser Dr Elizabeth Hall said the Colchester hospice had been ready to meet the challenge almost from the day it opened.

day it opened.
"We have not been asked to take an AIDS patient, but we are prepared to take any

sure that the precautions that are required would be

## NHS sticks by decision to cut funds

## Hospice offers AIDS care

COLCHESTER'S hospice announced this week that it is prepared to admit AIDS patients.

This decision comes only five weeks before the St Helena Hospice loses valuable NHS funding of £180,000 a year.

It costs £450,000 a year to run the hospice, and this task will be made even more difficult when a day centre donated to it opens this year. Work begins on the centre this month.

A health authority spokesman said the hospice decision on the admission of AIDS patients would make no difference to its decision to withdraw its funding.

The hospice, which serves the whole of north-east Essex, is also offering a counselling service to people involved in caring for sufferers from the disease.

## **Volunteers**

Hospice director Mr Keith Dallisson said these developments were logically in line with the hospice's stated philosophy of caring for the dying.

A series of meetings is being held to keep the hospice staff and the 300 volunteers who work there informed of the situation.

Asked if any volunteers had quit because of

## by WYN JONES

the hospice policy on AIDS, Mr Dallisson said they had not. He was also asked whether he thought the decision on AIDS would prove so controversial with some people that it could adversely affect fund-raising, on which the hospice depends heavily. He replied that he did not think the funding would be affected in

"As you can imagine," said Mr Dallisson, "we are very often asked if we would take in AIDS patients. Our philosophy is very clear on this point. St Helena Hospice has been established for the terminally ill, and it is open to all who need its special care.

"Therefore, if in our professional judgment any patient - AIDS patient or not - would benefit from the particular expertise which the hospice offers, then that patient would be admitted for care. "It is really not so much a question of

whether we would or would not admit an

St Helena Hospice.

AIDS patient, but rather whether the hospice would be the place for that patient to receive the best and most appropriate treatment. On those criteria, we certainly could be nursing some AIDS patients.

## Cancer

"Whatever the case," added Mr Dallisson, "we shall help where we can. We feel we can make a real contribution by offering to share our experience in counselling of patients, staff and relatives and those who are involved in the care of AIDS patients.

"How do the volunteers feel about it? They,

like the rest of us, have been pounded by a media which has tended to confuse rather than clarify.

"All staff, including volunteers, are kept fully informed, and an exchange of views is encouraged to remove any misgivings there may be. I do not envisage any problems.'

Asked whether the hospice would be able to cope with AIDS patients as the incidence of the disease grows, Mr Dallisson said there had always been hopes of expanding the 15-bed building. But he stressed that such expansion would not be linked in any way with the growth of AIDS.
See comment page 2

### by JUDITH BASTIN

AIDS plan at hospice

Town hospice set to take AIDS patients

Hospice AIDS offer protest

COLCHESTER health service union tion of the hospice.

over the role and func-

on the resources of an already under-financed

Soon after the hospice opened, this whole situation was filling the news. I felt strongly that we had a role to play, as did many staff. After quite a bit of resistance it was agreed we could admit people with AIDS or who were HIV positive. It is hard to explain now what an achievement this was. However, we had hurdles to overcome in this atmosphere of fear and ignorance.

Dr Elizabeth Hall, medical director

Image: Essex County Standard, 20th February 1987

420x420mm panels mk3.indd 10



Princess Diana was very, very good with the patients. I was delighted to see the day centre being used, it gave me a good feeling. The heart of the hospice is the people working there, the volunteers, the nurses; they have a very difficult job. Buildings are nothing else but inanimate, but the staff and volunteers are absolutely wonderful.

Robin Tomkins, who generously funded the day centre in memory of his wife, Joan

Pictured: Diana, Princess of Wales, visited to officially open the Joan Tomkins Centre on 26th April 1988



All these years later, it is an absolute joy to see St Helena Hospice fulfilling the vision of extending that level of care from the hospice building into the homes and hospitals of North East Essex, giving local people a choice. Looking back to that first day, it is a dream come true, seeing what one had hoped it would become and how it is still developing and moving forward. Hospice is not just a building but a concept of care.

Dr Elizabeth Hall

Pictured: Some of the people involved in the St Helena Hospice heritage stories project, oral histories recorded 2019-2021

## Appendix F

Life Stories Heritage artwork panels

## ST HELENA HOSPICE

# 66 life stories



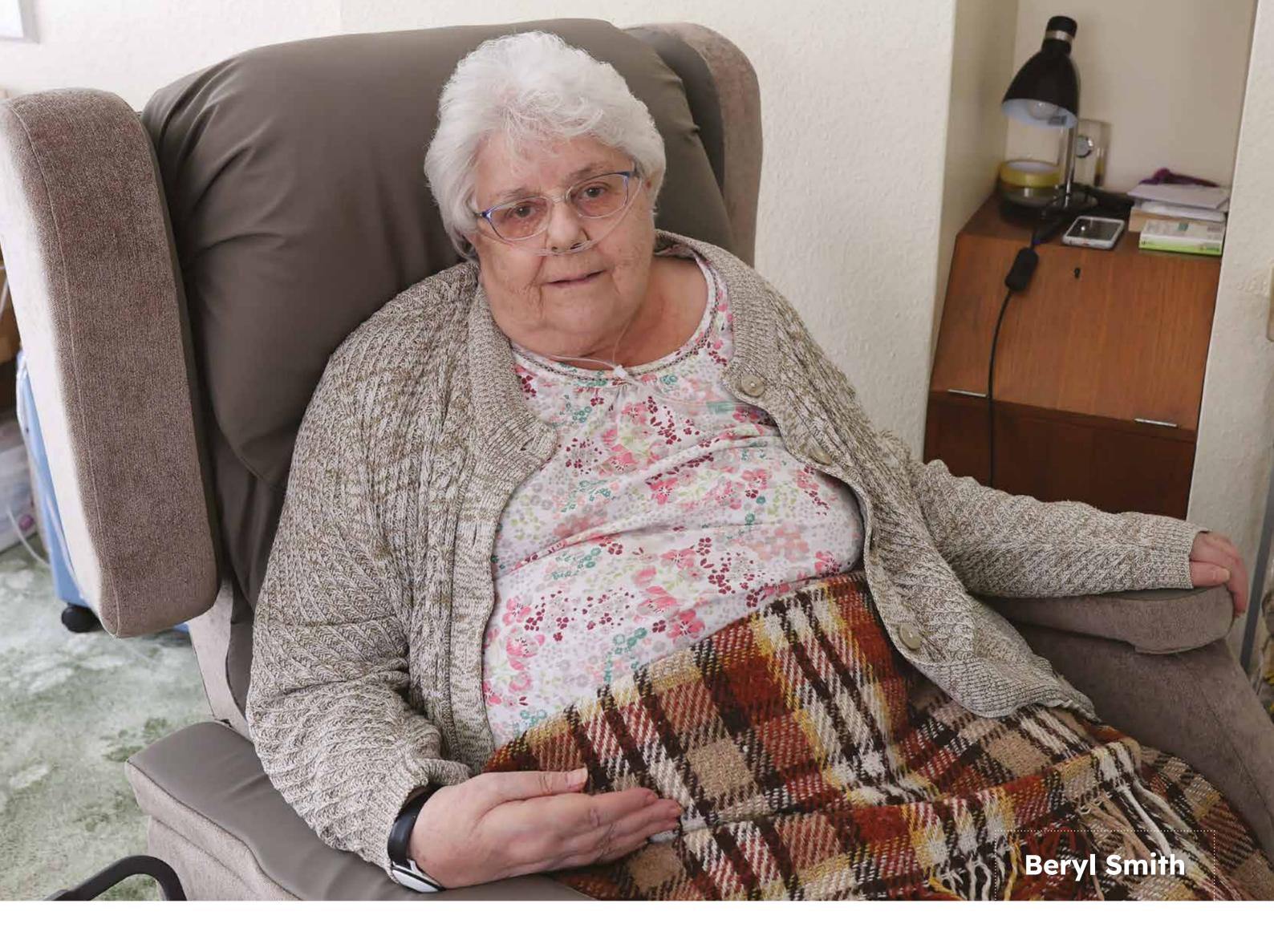






On my 16th birthday, my father came up to my aunt's house where I lived and he said to me 'look out there, son, what do you think of that?' And there was an old ex-army Norton 500 and she was the bee's knees. My father jumped on, I got on behind him and he took me into the countryside, and that is where I began my training to be a motorcyclist.

We used to go out for rides down to Brighton. I've even rode up the Devil's Dyke on a solo bike bumping one side to the other! It's great, it's freedom, because that was part of them days after the war; you got what you could or you begged, borrowed or stole it.



I was born in London right opposite the ladies' prison, Holloway. We had a couple of rooms at the top of the house and every time you wanted to go to the toilet, you went all the way to the bottom of the house and then you had to go all the way back up to the top of the house.

The main part of our childhood was the summer holiday going down to my aunt's in the Cotswolds. Oh, we had some lovely times down there paddling in the brook, doing fishing in the brook, only little tiny tiddlers. We just used to wait and wait and wait just for that day to come when we got on the train and off we went.



I really wanted to say my little bit to my daughter and son-in-law. I am in a wheelchair now, so it was a great joy for me that they were able to support me as I stood and read what I wanted to read and that they can then keep those words.

What was the greatest, greatest blessing for me was, I have four grown up children and two granddaughters and they all came together. The whole family were there, that meant a lot to me and to Anna as well. She was happy to see me looking happy and content and just being a mother of the bride and having a little blubber as mother of the bride. That was a very, very special day.



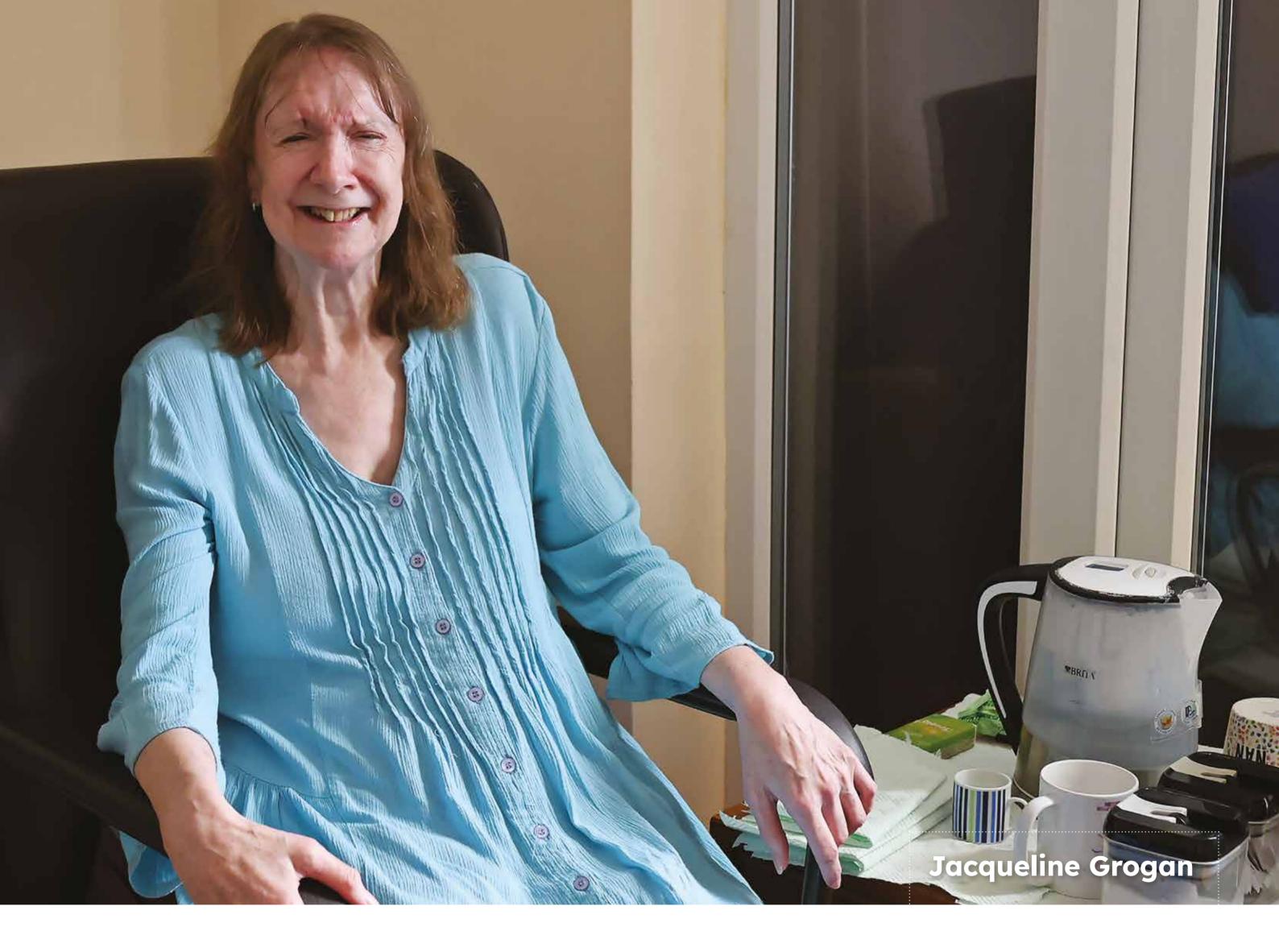
I love Christmas! Family time. Our Christmas Day looks like me, my brother, my mum and my step dad all in Christmas pyjamas. We spend the whole day together, do presents in the morning, the Christmas fry up, and then Mum opens the wine and starts the Christmas dinner. And then we watch Christmas films and just spend time together.

I'm a really good gift giver. I pride myself on my gift giving and I actually prefer seeing other people open my gifts to opening my own presents. We have to wait to decorate our tree because Mum said that I'm not allowed to decorate in November, even though I want to, so as soon as it's the 1st December, I'm like, it's Christmas!



I've lived in Harwich all my life. I used to love going in the water, I love a swim, I used to go in at 7 o'clock in the morning until 12 o'clock at night. My missus used to moan like hell cos she couldn't swim! Used to be full of people on the beaches, all up there on the promenade. People used to open their doors, give you a cup of tea.

I had a job at the coal yard loading up all the coal ships what come in. I left the boats and had to go in the army. I never told me mum when the letter come, I just left a note on the table saying to me mum *I'm gone away for a little while*.



Because I love the sea, my son took me to Walton on the Naze and there's a Hell's Angels biker café there. This man, Dave the Donk he was called, had a trike with a double saddle, said he would take me. So I got out of my wheelchair, walked over to the bike, got my dress up like that and just climbed on.

He took me all along the coast road sounding his horn and waving. It was the most wonderful experience I ever had in a long, long time, many years. I was in my element. He was saying 'tell me if I'm going too fast' and I'm like faster, faster! I am a daredevil. I love the speed.



All I craved as a youngster was to ride horses, much to my parents' disapproval because I think they thought that sounded quite expensive, and I think they thought that sounded dangerous. But eventually they gave in and I learnt to horse ride with friends at the age of about 7.

At the age of 18, when it was finally deemed that I could afford one myself and be able to look after it myself, I bought one with my first bonus money. He was very beautiful and adorable and looked after me very well. He was with me for 25 years or more, a long, long time, in fact, longer than my mum. Every spare bit of money went in a pot towards the horse, I had a lovely time.



Probably been married 42 years. We just went off, left a note for my secretary on the desk saying just going off to get married. Lunchtime, the Registry office was only 100 yards away.

It was when I was at a photographic company on cruise ships for passengers to have their photos taken, so a lot of travelling involved. We always had great holidays. We had very well-travelled children, even though the younger one would say 'why can't we go camping like our friends, why do we have to go on a cruise ship?' We have two girls, four grandchildren, it is perfect.

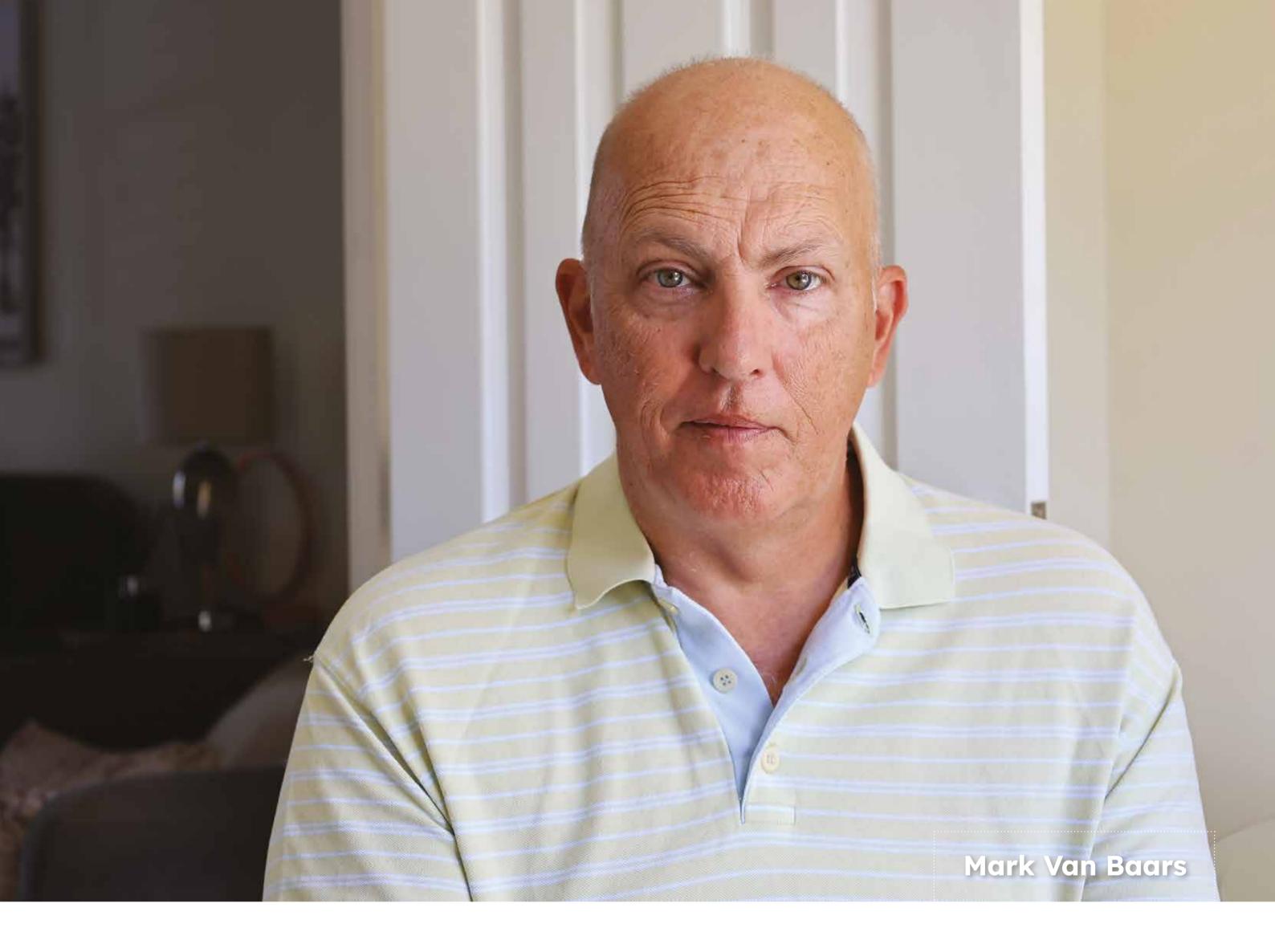
Life is short, make the most of it. We're born, we live, we die. I'm here to enjoy myself.



Creativity, I've always been that type of person with my photography and on the arts side of things. It's like this table; sand it down and tile it and make something beautiful.

I am a qualified salsa instructor, 18 years I've been doing that. I'd go to Blackpool, all over the country. When I was younger I did ballet as well. Because of the dancing and photography, I've always been confident, so when it comes to living, I feel that I just want to keep going because of the way I am as a person. Makes me feel good.

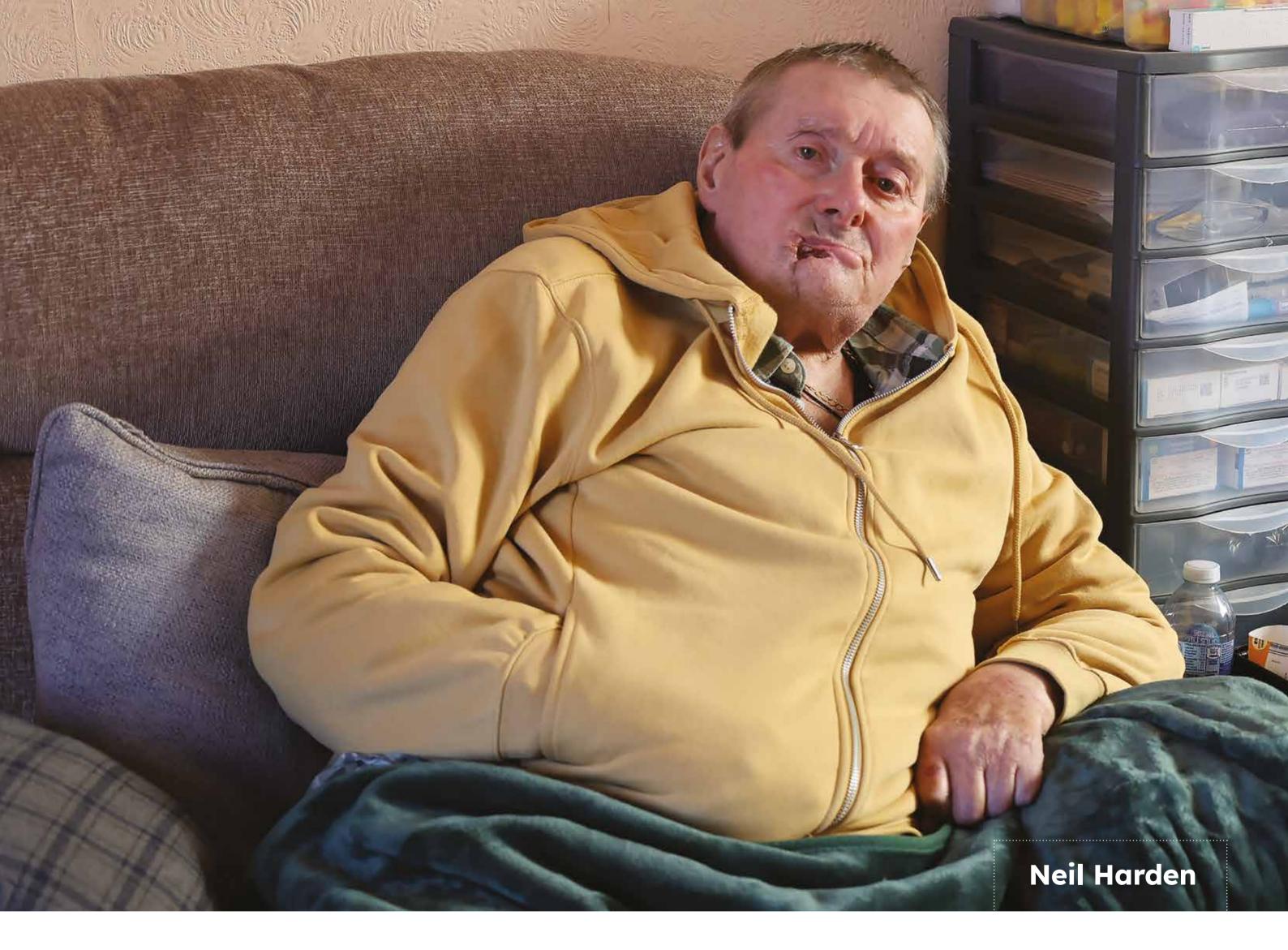
I've got carpentry and bricklaying too. My dad's motto was 'skills pay the bills', so I say learn as much as you can through life.



My mum's sister was living in Frinton and they were boat mad and built their own boats.

My parents would take me out on the boat. We had lots of fun times doing all kinds of things; sailing, crabbing, fishing, even just rowing round the backwaters was fun.

Sailing... sailing makes me happy. I love the feeling when you get a gust of wind and the boat reacts really well, it's quite surprising how quick they go. It's the feeling you get, just the wind pushing you along. I like the freedom, you can go to places no one else can go. The peace and quiet and being lost in the world is lovely.



I'm the oldest of seven, big families in them days. Went to school in Greenstead Road, that were good days, surprising what I got up to! It was all farmland up here then.

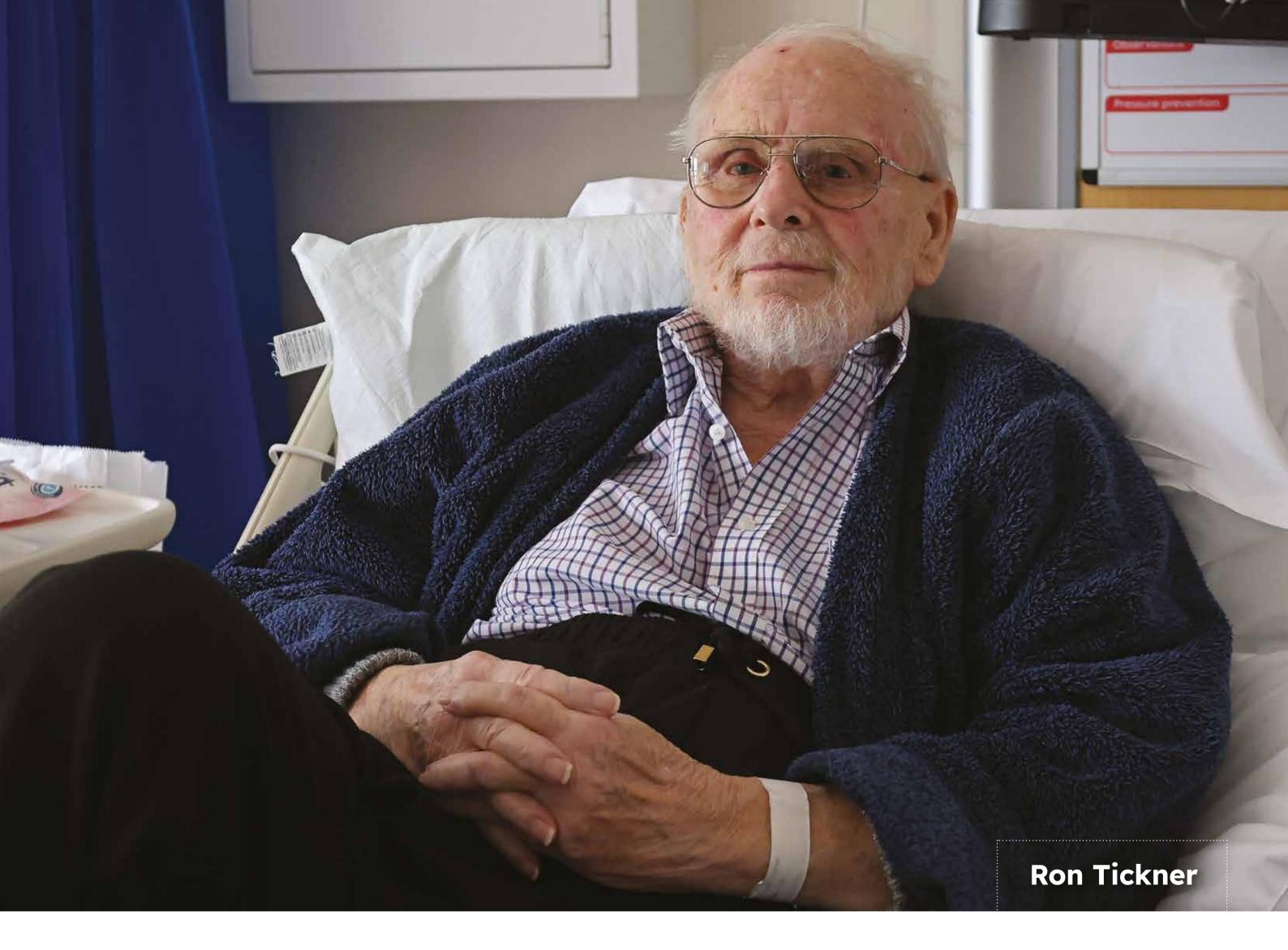
Lived here in this house since I got married, 55 years. I lived for a while in a maisonette then moved to here because we done the change through the council and after a few years, Margaret Thatcher did this Right to Buy and I bought this house.

The 1960s were good. The '66 World Cup was good. Used to like life, socialising and dancing, rock n roll. Used to sing on a lot of karaokes, used to love them. I was a football man, played football until I was 45.



When I was in Hull, they had wonderful trawlers that went out to catch mainly cod. I let it be known I wouldn't mind a trip and one summer I went for three weeks up to Bear Island in the Arctic and we caught 300 10-stone kits of fish. It was absolutely amazing. We caught quite a big halibut and they gave me it at the end of the trip. I took it home and we had it for our Christmas.

That was wonderful and it made me even more love the idea of the sea. I said I think we ought to go look at some boats and we drove from London to the coast, Tollesbury, and bought a 23 foot yacht then and there. Well, we had the most wonderful time in that boat.



We lived on the edge of London and we caught the edge of the Blitz. Several times all doors and windows blown out, bombs dropped, fortunately not too close to our house. I remember hearing and seeing a doodlebug, hear the buzz of the engine, then it cut out and dropped somewhere just at random.

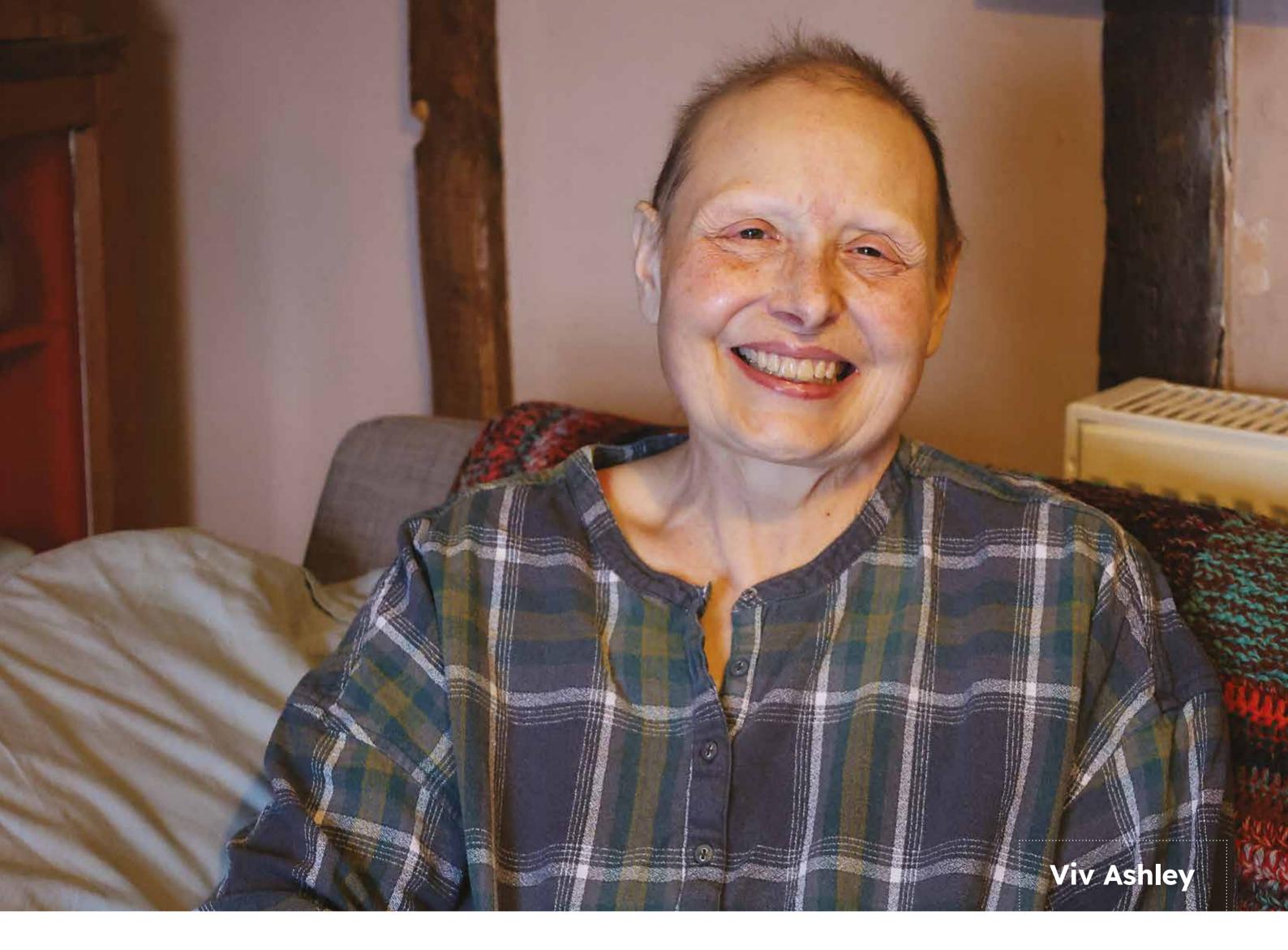
As children we used to collect shrapnel. After a raid you could go outside, walk along the street and there'd be lumps of red-hot shrapnel lying around from shells. We had an Anderson shelter in the back garden, just corrugated, and you'd go down and sleep in the shelter.

Hard times followed the war with the food rationing, clothes rationing, it was hard. We weren't the worst off, we were lucky.



I saw Donny Osmond on telly in the early 70s, I didn't know who The Osmonds were and my love for Donny started then I think. It was in 1975 my sister took me on a surprise trip to a concert, to The Osmonds, somewhere in London. I'd never been to a concert before. I was like, I'm in the same room as Donny Osmond! It was amazing.

I'll never forget during one of his songs I just sat down crying and as I looked up, he raised his hand and I thought he can see me, he's seen me. Donny Osmond's seen me! I'm perfectly calm until I see him and I am all of a sudden that mad woman!



Some of my happiest memories, well, *the* happiest memories, have been associated with the sea. We travel a lot to Scotland in our camper van where you can literally camp on a beach in certain places. What is it about it? It's about association. It's about the colour, it's about the movement. There's something very refreshing about the sea. Something quite healing about it.

I love losing myself in a book and it's particularly wonderful with audio books because you can lose yourself whilst doing something like painting or gardening, two of the things that I've grown to love doing. So yes, listening to a book whilst gardening or painting, they're my favourite kind of spaces to be in when I'm not with Rachel.