

# YOU MATTER

## BECAUSE YOU ARE YOU TO THE LAST MOMENT OF YOUR LIFE

### A **PASSION FOR LIFE** UNTIL THE **VERY END**

Dame Cicely Saunders pioneered the modern palliative care movement and drove the medical profession forward through her originality and innovation, leaving a legacy replicated worldwide.

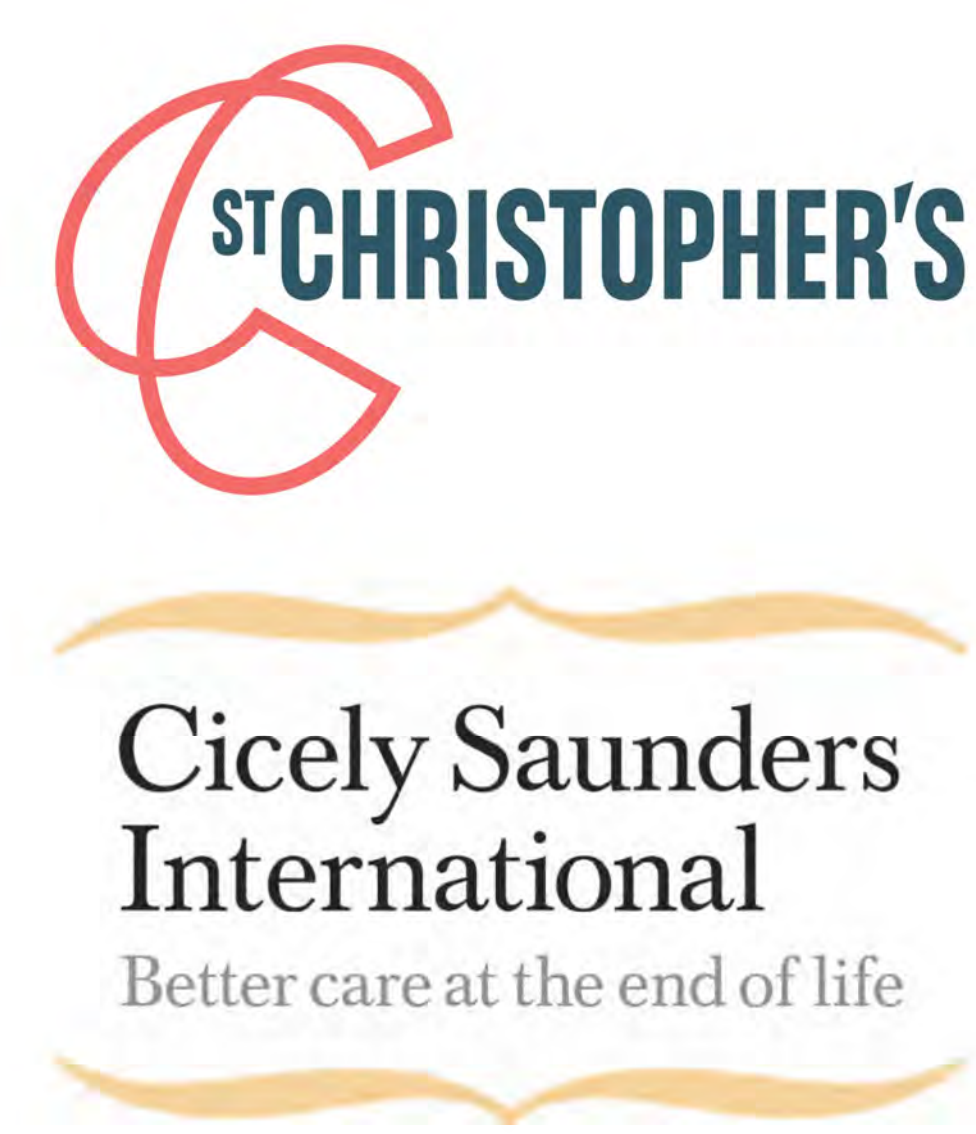
She is a remarkable example of a woman who viewed her entire life as an enthusiastic adventure, provoked by every circumstance: an unhappy childhood, a stormy home life, an unorthodox academic career, the Second World War, a late marriage, breast cancer, and the numerous people she met (above all David and Antoni).

Guided by her **vulnerability of heart** and **diligence of mind**, 60 years ago she founded the first modern hospice in the world as the result of a 20-year-long open-minded and fully committed personal journey rather than a carefully planned goal.

**'You matter'** showcases Cicely's revolutionary ideas in palliative care from the development of multidisciplinary team models to focused care for terminally-ill patients, integrating expertise on total pain and symptom control, compassionate care, teaching, and clinical research alongside bridging her approach from St Christopher's Hospice into the community.



***Are you willing to share  
“your mind and heart” ?***





# VULNERABILITY OF THE **HEART**

Cicely experienced a **difficult childhood** because of a turbulent relationship between her parents, who eventually separated. She also often felt **isolated** from her peers at school.

*"[...] my parents weren't very happy together, and even though we were children and didn't fully realise it, this fact somehow affected us. I couldn't fit in at school; I was too tall, I talked too much... My father was determined to give us a good education, even a university one [...]. When I turned 14, without even discussing it, he told me he was sending me to Roedean. [...] I ended up in a single room, alone, and it wasn't at all easy to make new friends. It was a pretty unhappy time. In addition, at the end of each day, I had to do corrective exercises for my back."*<sup>1</sup>



*"If I think back to my nurse training during the Second World War, I believe that it was fundamental in teaching me the importance of personal commitment and care for the small details. Often, we didn't have anything else to offer apart from ourselves."*<sup>1</sup>



Cicely belonged to a London upper-middle class family. In 1938, she enrolled to study Politics, Philosophy, and Economics at Oxford University. After the outbreak of World War II, however, she felt compelled to change her career path and decided to become a **nurse**. This experience was pivotal to her formation and gave a foundation to her career. Unfortunately, because of her chronic back pain, she was advised to discontinue nursing, which she had embraced with **enthusiasm**, after qualifying.



# I WILL BE A **WINDOW** IN YOUR **HOME**

Cicely then became a **social worker**, but never really enjoyed this new occupation. She continued to search for her true mission. At that point, the encounter with **David Tasma**, a terminally-ill Polish patient, while working at St Thomas' Hospital, completely changed the course of her life.

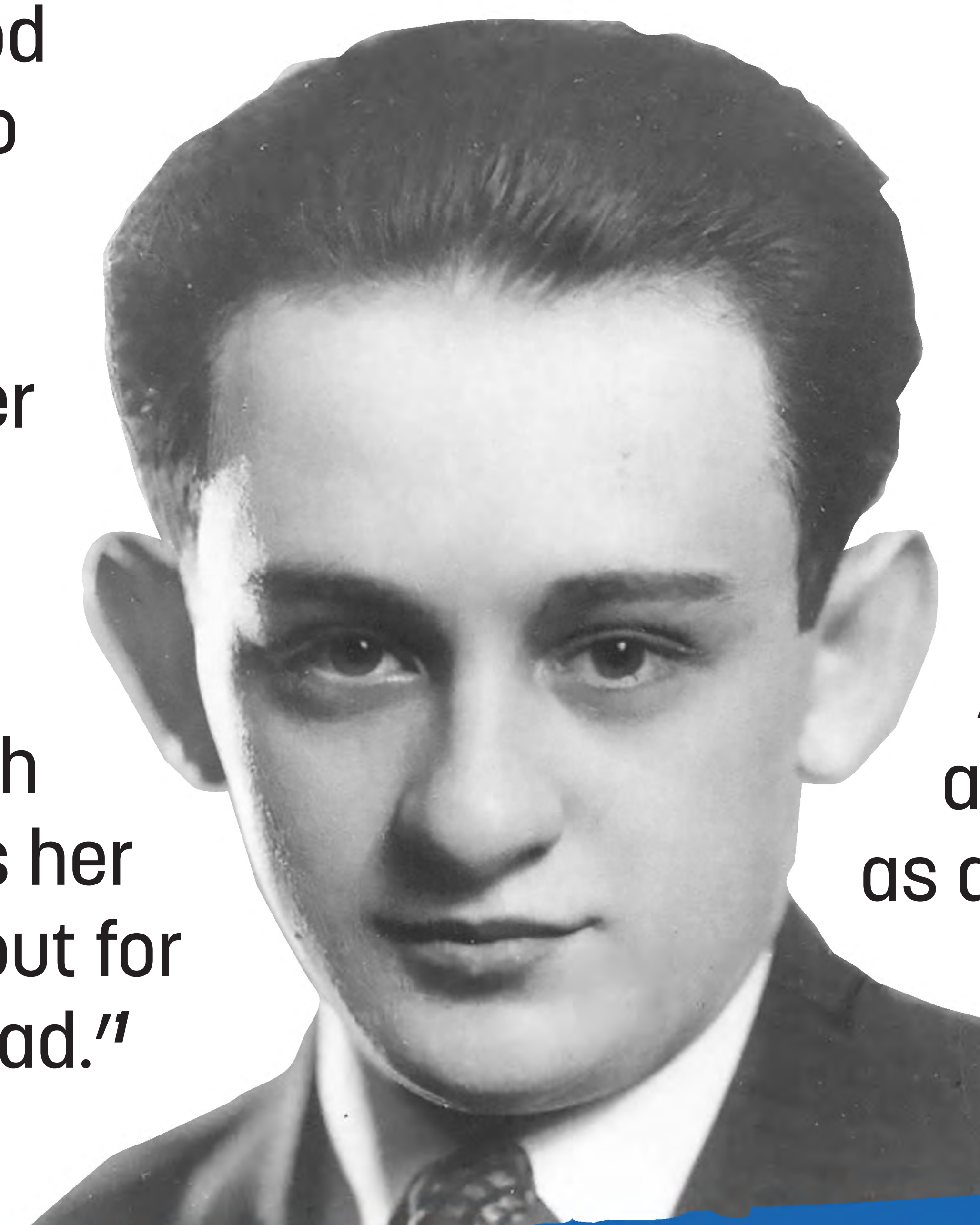
*"One day, [...] I suggested I might read some of the Psalms to him. He replied: 'I only want what is in your **mind** and in your **heart**.' [...] what we really should make available to the terminally-ill patients: [...] to use our minds, all the scientific rigour, all the research, all the learning that could be done but always with the friendship of the heart."*<sup>1</sup>

**When David Tasma died on 25<sup>th</sup> February 1948, he left Cicely a gift of £500 and he told her: "Let me be a window in your Home."**<sup>1</sup>

Cicely's bond with David illustrates how she always allowed her heart to be vulnerable in her relationships with others, in particular with those people she loved and eventually lost. She looked after him until his very last instant. She considered him as a pivotal source of inspiration and the **'Founding Patient'** of the **movement of modern hospices**.

Cicely devoted her life to the dying because of David. When [she] became a Christian, she asked God "What do I have to do to to say thank you and serve?"<sup>1</sup> Three years later she got her answer through meeting David.

'Cicely's religious journey had started with the intellect: now it was her heart that was calling out for sustenance, not her head.'



After his death, she worked again with terminally-ill patients as a volunteer nurse at St Luke's Home for Dying Poor in Bayswater.



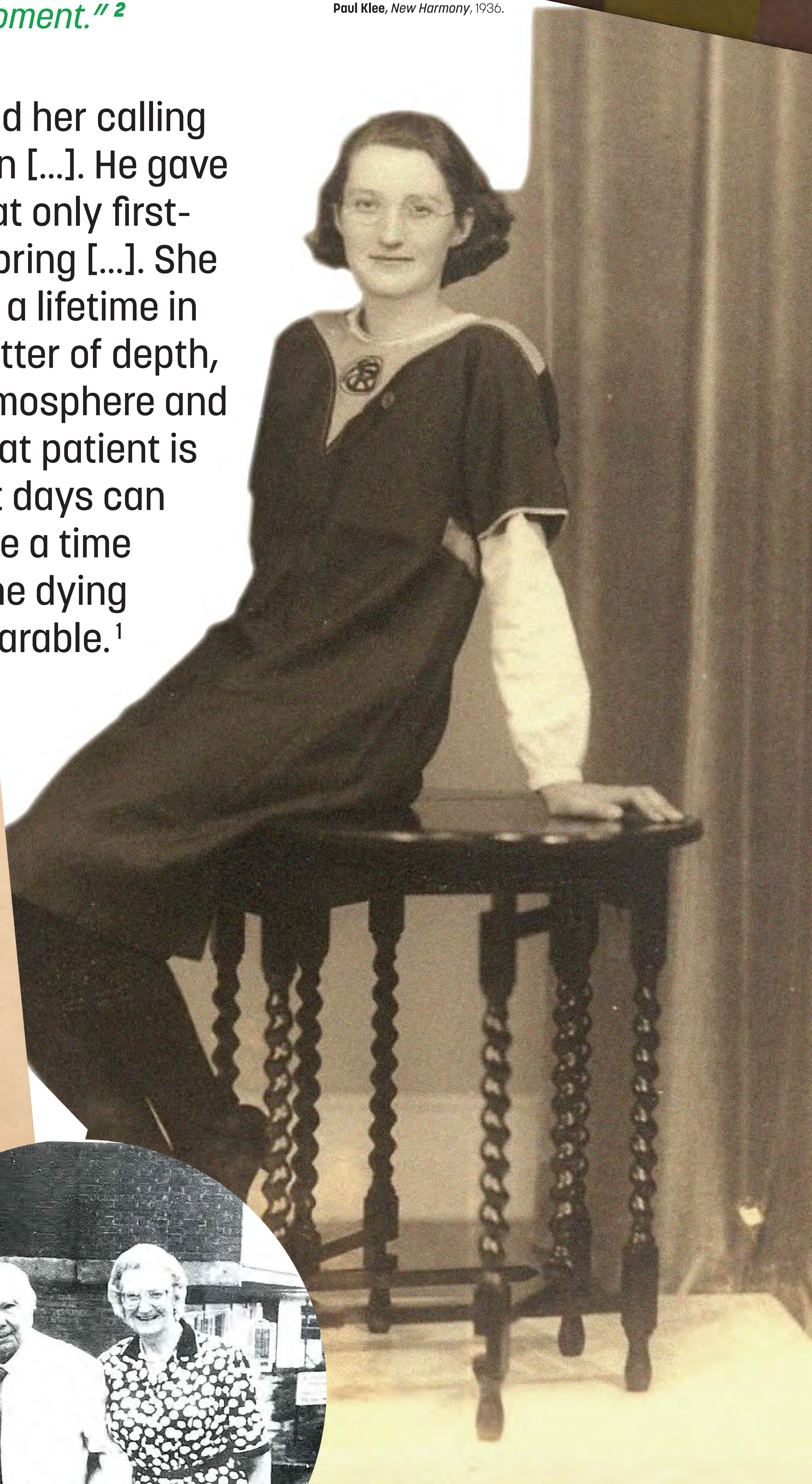
# THE “PROFUNDITY” OF TIME

At St Joseph’s Hospice, after qualifying as a **doctor**, she assisted **Antoni Michniewicz** who was instrumental to her understanding of the grieving experience. They fell in love and lived an intense, joyful but bittersweet relationship until his death.

*“My falling in love with Antoni was very peculiar. We had 3 weeks for us [...]. It made me understand what it is to lose someone, to be bereaved. Antoni was the most important person to me and it was very difficult to overcome losing him, because everything in him was extraordinary. I remember him saying to me one day ‘I can’t **offer you** anything else apart from **my suffering**’ but I said [...] it is **you** who is **giving me so much**’. [...] it was a very intense moment.”<sup>2</sup>*

David [...] had helped her to find her calling [...]. Now Antoni lit up her vision [...]. He gave her [...] that special charge that only first-hand intense experience can bring [...]. She learnt that it is possible to live a lifetime in a few weeks; that time is a matter of depth, not length; that in the right atmosphere and with pain controlled so that that patient is free to be themselves, the last days can be the richest: that they can be a time of reconciliation that makes the dying peaceful and the mourning bearable.<sup>1</sup>

Paul Klee, *New Harmony*, 1936.





# DILIGENCE OF MIND

Through her relationship with the terminally-ill 'founding patients', Cicely identified the urgency for a radical change in the way all their needs were addressed in the 1940s.

As her professional journey evolved, she embodied within herself key figures of the future multidisciplinary palliative care team. The revolution she started drew vital energy from the powerful combination of her **personal motivation**, **professionalism**, and **determination**.

## A change in pharmacological pain management.

Having seen many patients either in agonising pain or comatose, she was surprised to find those at St Luke's much more comfortable and alert almost until the end thanks to the practice of the '**regular giving**' of painkillers rather than waiting for the patient to report pain.

In 1958 she obtained a **research scholarship** from St Mary's Hospital to focus on pain management at St Joseph's, a hospice for the dying poor founded by the Irish Sisters of Charity. Working as both doctor and researcher, Cicely developed a record-keeping system of over 1,000 patients and, challenging the stigma around prolonged use of opioids, she demonstrated that:

- regular oral administration at the **lowest effective dose** relieved pain adequately;
- their appropriate use in end-of-life care did **not** cause **addiction**;
- tolerance was not a concern.

## Therefore...

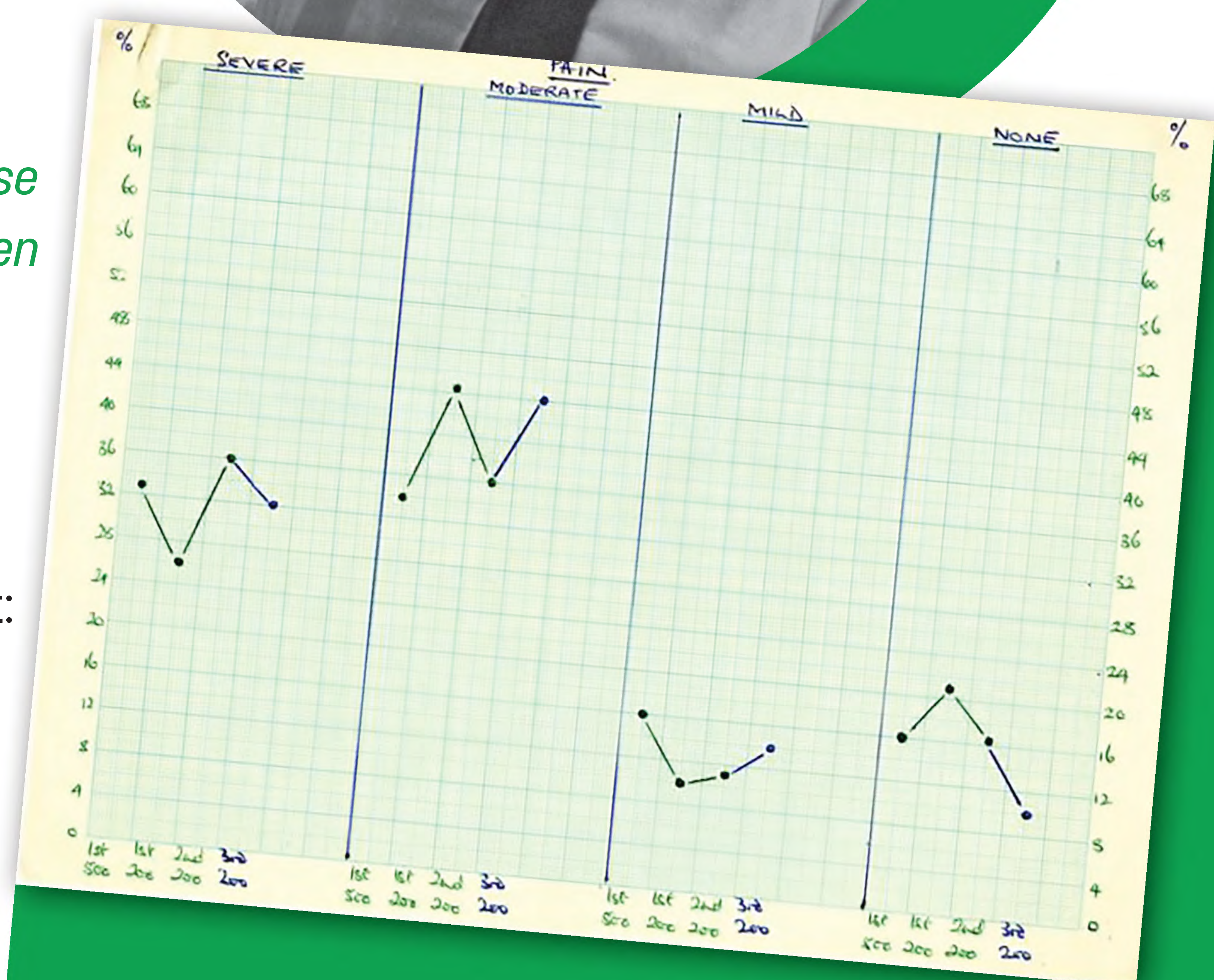
*"Constant pain needs constant control, [...] drugs should be given regularly so that pain is kept in remission all the time. If the patient has his own dose of analgesics given to him as a routine, he is not then nearly so dependent, either upon the staff and the drug."*<sup>3</sup>

Research into memories of families of patients who died at St Christopher's during 1977-79 showed that:

- 33% had no pain at all during the final phase of their illness;
- none suffered from extreme or very severe pain;
- only 7% had severe pain;
- 60% had mild to moderate pain.<sup>4</sup>



Paul Klee, Monument in a fertile country, 1929

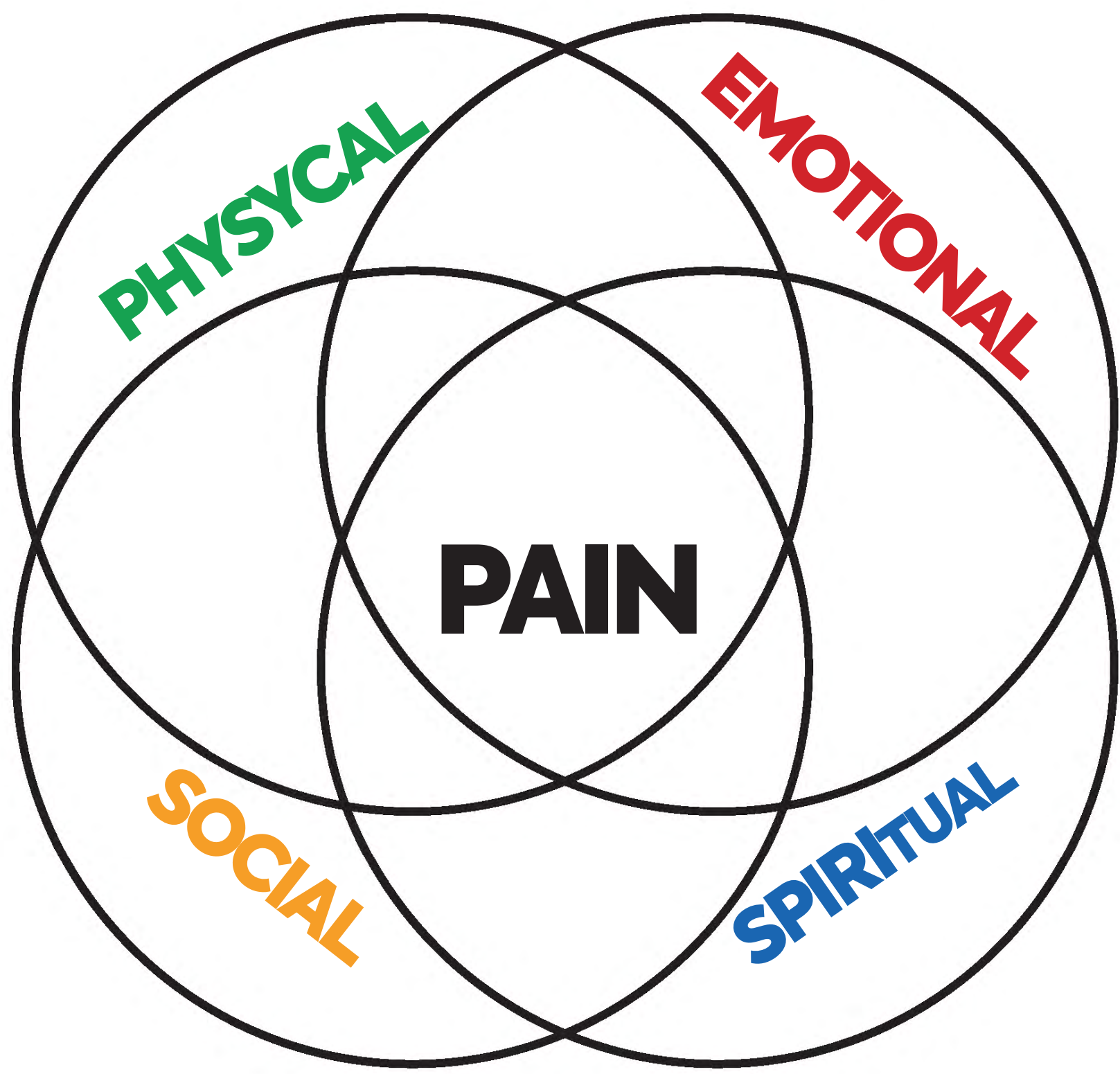




# TOTAL PAIN AND THE NEED FOR HOLISTIC CARE

*"The greatest **sorrow** of a dying patient is the ending of relationships and responsibilities. We live in our interchange with others and as encroaching weakness leads to the change of roles, as the wage earner can no longer work or the housewife has to hand all her activities in caring for the family to others, it is hard not to feel useless and humiliated."*<sup>5</sup>

Cicely's innovative concept of **total pain** provided a revolutionary way of conceptualising the complexity of patients' suffering. A systematic approach to the control of physical pain was required, but special attention had to be paid to the person's four needs:



## DILIGENCE OF MIND

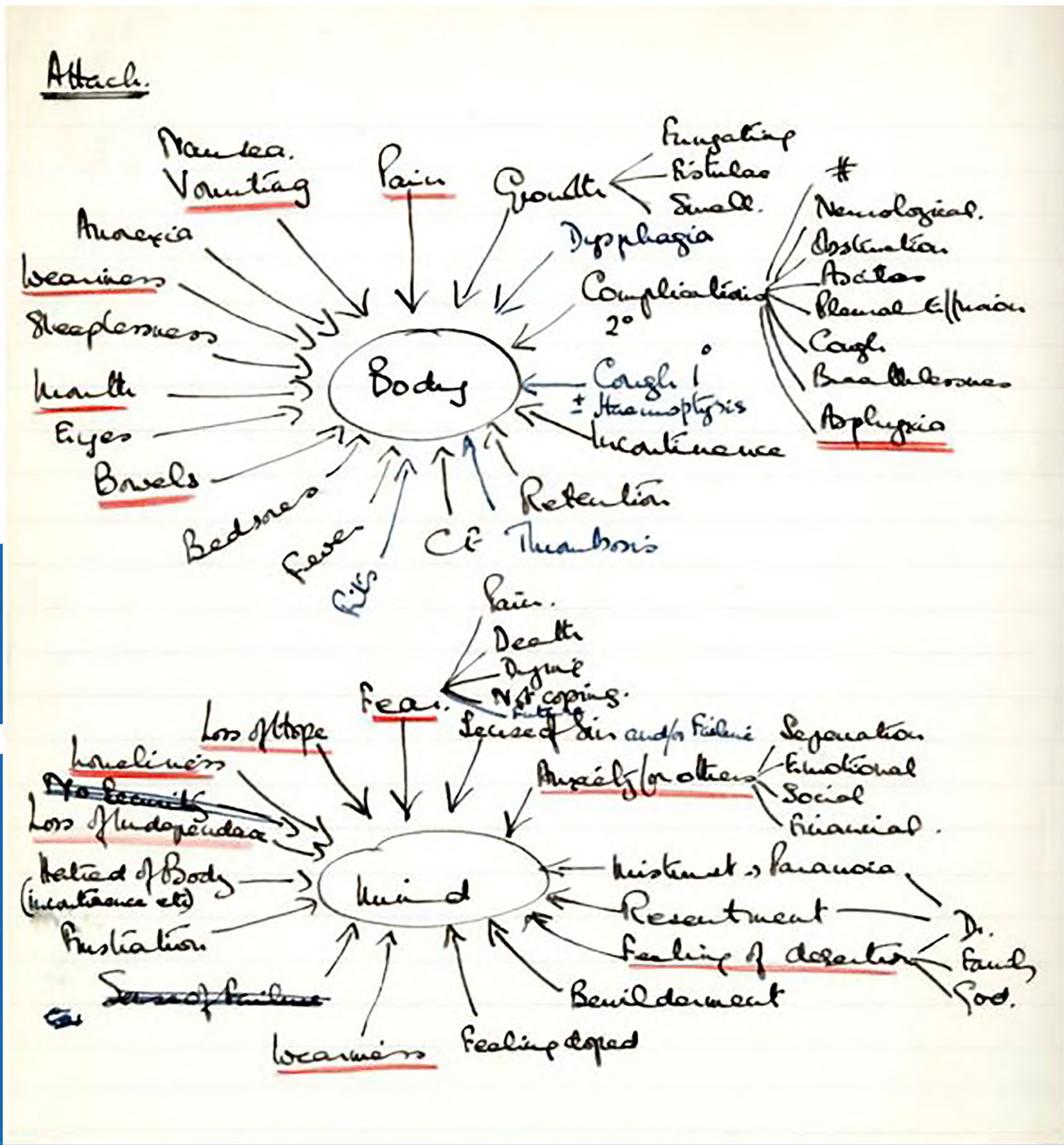
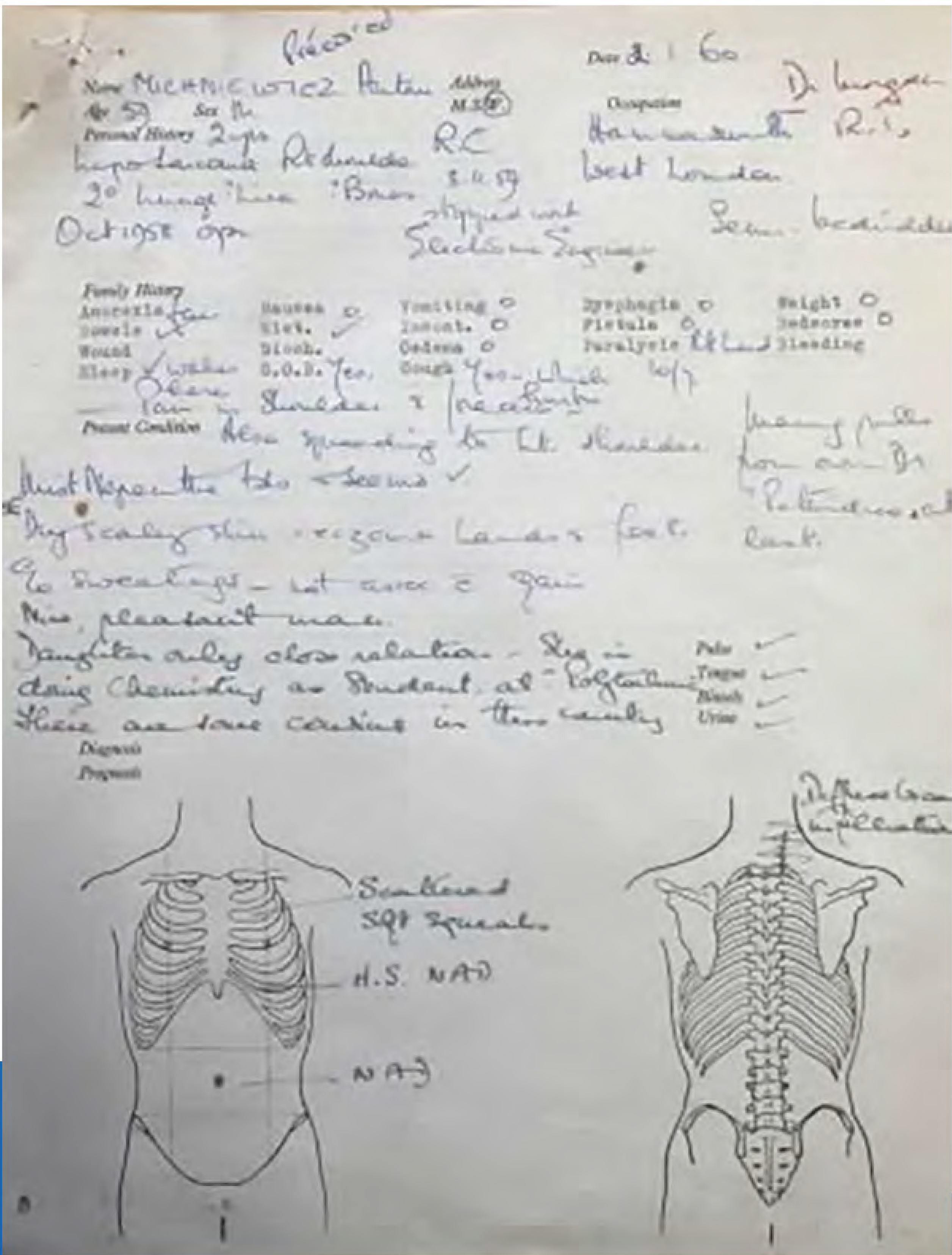
In response to the disillusionment of healthcare professionals dealing with the terminally-ill, Cicely aimed at building a relationship of **trust, communication, and acceptance** between doctors and patients. She sought to ensure the patients' remaining time was as comfortable and meaningful as possible, while keeping them pain-free and mentally alert until the end.

She always emphasised the idea that there is a positive achievement in dying, challenging the mentality according to which the only aim of medicine is the cure of the disease, while *"the dying patient is hidden away. Doctors are brought up to think of death as a defeat."*<sup>6</sup>

*"These patients are not looking for pity and indulgence but [...] we should look at them with respect and an expectation of courage [...]. We will be seeing patients who go along the path which leads from the honest but wistful plea 'I do not want to die' to the quiet acceptance of 'I only want what is right'. We will not only see acceptance but also a very real joy, the true gaiety of someone who has gone through doubt, fear, and unwillingness and come out the other side."*<sup>5</sup>



Paul Klee, Monument in a fertile country, 1929





# ST CHRISTOPHER'S HOSPICE

*"St Christopher's Hospice began when David [...] talked of his needs with me when I was still a social worker [...], of his hopes for people who would come after him, and of certainties he would not see. Through him a demand was made on me – I had to go and do something about it, however long it might take."*<sup>1</sup>

***"I did not found the hospice; the hospice found me"***<sup>7</sup>

It was 19 years before the first patient came past David's window and the first members of staff began to try to give what was in their minds and in their hearts, to bring all they could summon of skill and friendship to relieve the manifold distress. At St Christopher's, under Cicely's direction, there was increasing interest and development of the concept of the '**person**', particularly in their family context, within their network of relationships, and in the way they face their physical deterioration. This was a hallmark of hospice care; whereas, previously the focus was purely on medical issues.

*"[...] all the work at St Christopher's should stem from respect for the patient and very close **attention to her distress**. It means really looking at her, learning what this kind of pain is like, what these symptoms are like, and from this knowledge finding out how best to relieve them."*<sup>5</sup>

**Patients were encouraged to describe their experiences, in **prose** or **poetry**, with **paintings** and **drawings**. Their works were windows into their minds and hearts of their suffering.**



Paul Klee, Monument in a fertile country, 1929

## ST CHRISTOPHER'S OPENS ITS DOORS IN 1967

Cicely welcomed patients and tirelessly involved the families of healthcare workers in the life of St Christopher's, where a sense of community was breathed. We may be small specks of dust in the immensity of the galaxies, but [...] the Hospice's welcome to each person, patient, family, staff or volunteer, is simply:

***"You matter because you are you, and you matter to the last moment of your life. We will do all we can not only to help you die peacefully, but also to live until you die."***<sup>1</sup>

She adopted a setting which gave a real feeling of security to patients and staff: *"they should all desire to make St Christopher's a home to all who come. [...] A community of unlike. [...]"*

*Everyone has a commitment to listen here, whether doctor or counsellor. A lot of what we are **giving** is **ourselves**, not just our skills."*<sup>1</sup>



# AN ETERNAL AND HARD LOVE

## ETERNAL LOVE

**4<sup>th</sup> August 1960.** *'O Lord, our wealthy place was tonight when he spoke of his Saviour, [...] and we were together in Thee. O may we please have a little longer, but please may it all be held and hidden [...] for Thee only. In Thy Name, Amen.'* [...]

I just took an hour, [...] I couldn't help it. We talked of photos, [...] holiday. We couldn't hold hands – but, [...] we each knew the other wanted to, so it was all right. [...] I tried several times but couldn't leave. And at the end when I said, "I love you, I love you" very softly...

He said: "I know, I too, but for you hard."

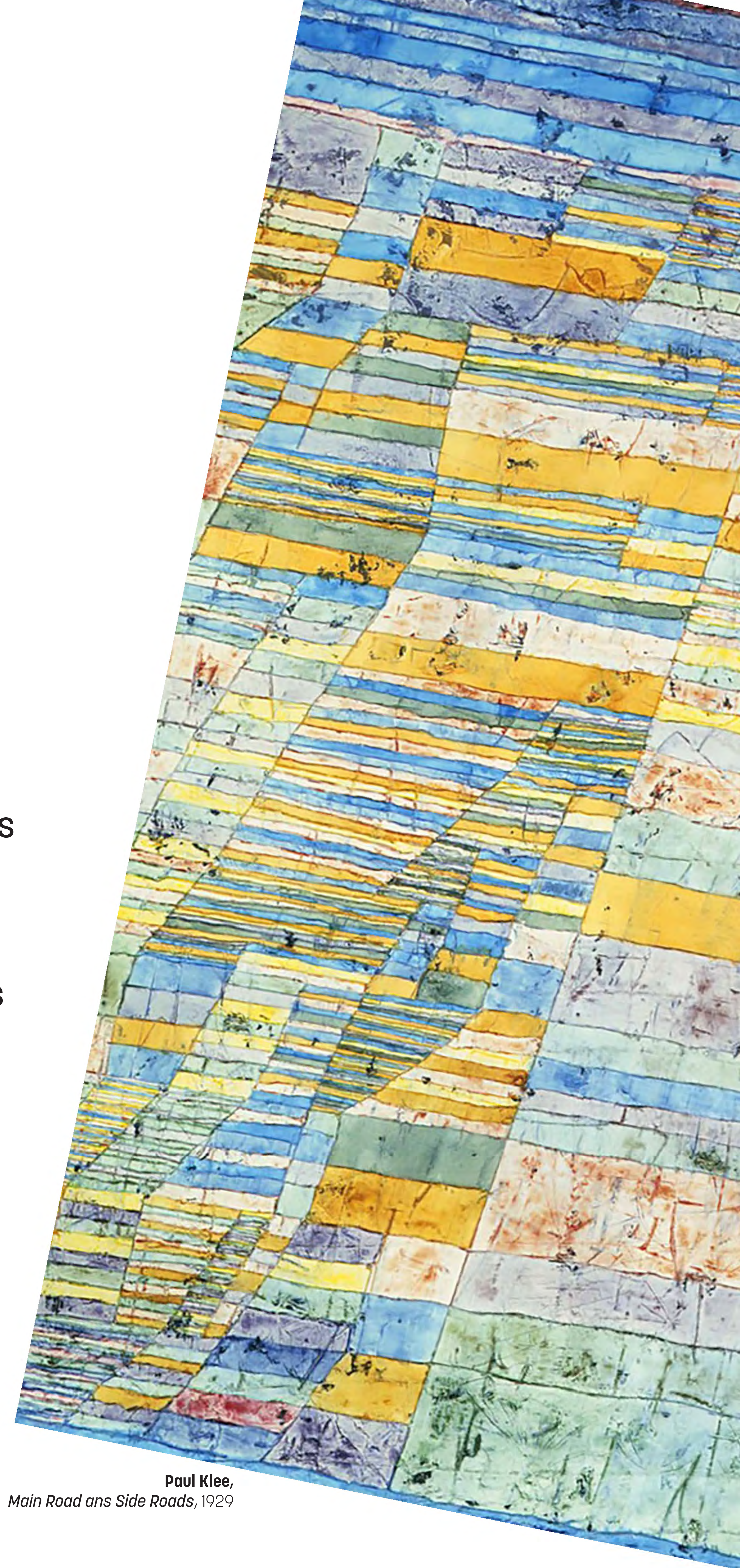
And I said, "We are one in Christ Jesus," and his face lit up as he looked at the Crucifix in the next ward and said, "I can see my Saviour." I looked at the one above him, for that is what reminds me of [...] only where, we meet and love.

So, I said, "**He is my Saviour too**, so that **wherever we are, we are together.**" <sup>1</sup>

## YET HARD LOVE

**7<sup>th</sup> August 1960.** [...] It took a bit of getting across, but he understood and agreed and we sat longing to hold hands and not daring to do so. And he was rather low and said "Why short breathing?" and I said "Lumps there." and he said "Anything to do?" and I just closed my eyes in misery. But he is calm and quiet. He said that he was sorry for me.

**"For me it is all right, for you it is hard."** And I said something about Eternity, but he was not easy to comfort. I said, "My true love hath my heart and I have his... true?" He said, "Yes, but for you, hard." I said that **I was made rich** and happy, but he was yearning for longer here... and we held hands an instant. <sup>1</sup>



Paul Klee,  
Main Road and Side Roads, 1929

*"There is **room in one's heart** for more than one **person** and no one will take another's place."* <sup>1</sup>

## LOVE AND PAIN

[...] He cannot save us pain because that is the way of love, and only when love accepts pain, can we be born again. **He accepted pain because of His uttermost love**, and He gives us His life... but **we have to come the same way, with Him and in Him.** [...]

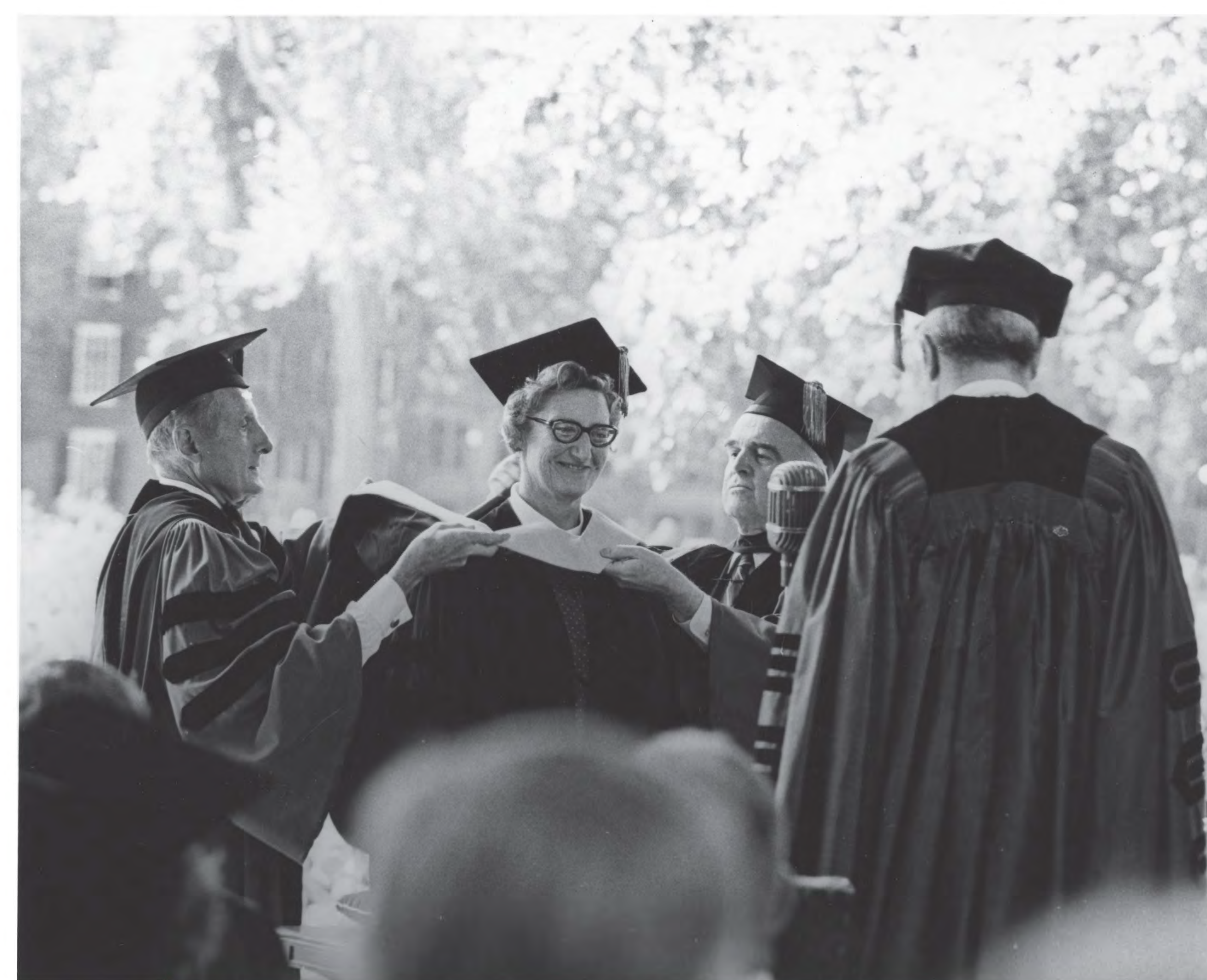
O my love, you gave me freedom and peace and quietness in Our Lord. You gave me Our Saviour in a new way. [...] I am grateful and although I fall back again [...], the remembrance of you is still strong to give me healing and peace on Our Lord. [...], you are in Him and perfect and perfectly happy. I praise Him for you and I believe that in praise, I come a little bit nearer to you. [...] do not let me clutch at you, nor burden you. [...] be happy and blessed forever [...].<sup>1</sup>



# CICELY'S LEGACY REACHES ME

## THE MODERN HOSPICE MOVEMENT

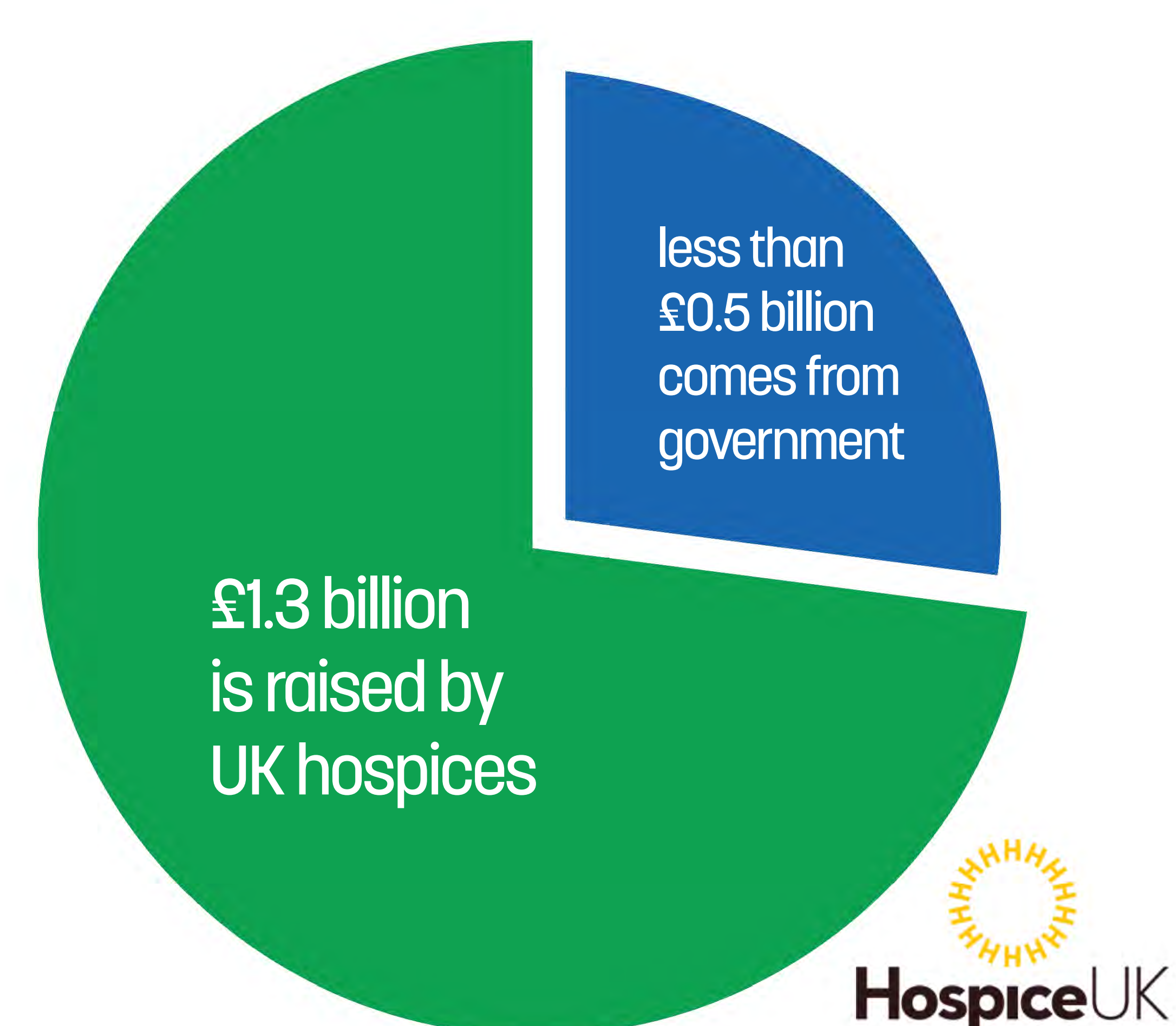
During a 1963 lecture at Yale University, Cicely spoke about her idea of specialised care for the dying. Among the audience was **Florence Wald**, Dean of Yale School of Nursing. After spending a month working with her at St Christopher's, she dedicated herself to bringing the principles of modern hospice care to the United States, establishing the first one outside England in 1971. The Hospice Movement has since spread throughout the world.



## PALLIATIVE CARE PROVISION IN UK

- Nearly 240,000 patients a year receive hospice care across the country.
- Despite this, over 100,000 people die annually without receiving the palliative care they require.
- Unfortunately, referrals are often made very late in the illness process. <sup>8</sup>
- A recent public survey demonstrated 65% of responders feared poor access to this service, while 41% thought not enough funding goes to the specialty.<sup>9</sup> In fact, less than one third of it comes from the NHS, with the rest from charities. <sup>8</sup>

Despite all its limitations, the UK has been consistently rated first in the international rankings on quality of end-of-life care across the world <sup>10, 11, 12</sup> highlighting Cicely's legacy and the need for the improvement to palliative care access.



**Her objections to euthanasia were not based on her religious convictions or her views on the sanctity of life, but on the knowledge of what medical care could do. <sup>1</sup>**

## MORE RECENTLY... IN PARLIAMENT

The recent debate on assisted suicide has provided an opportunity for a renewed attention to Cicely's unique contribution.

*"I learned a lot about the need for improved end-of-life care when writing some years ago about the life of Dame Cicely Saunders [...]. She was rightly shocked by the **marginalisation** of those who were called the 'incurables', and what she saw as their abandonment and betrayal by the conventional medicine of the time. Her **brave**, groundbreaking investigations, and relentless campaigning showed how the last months and days of someone's life can be **dignified**, worth living and even pain-free." <sup>13</sup>*

**"[...] we have to [...] help the dying patient and his family in every possible way to find this kind of security. This situation, which cannot be changed, can be transformed... They do not need just sympathy and sedatives, but something that was summed up with the words: 'watch with me'". <sup>14</sup>**

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