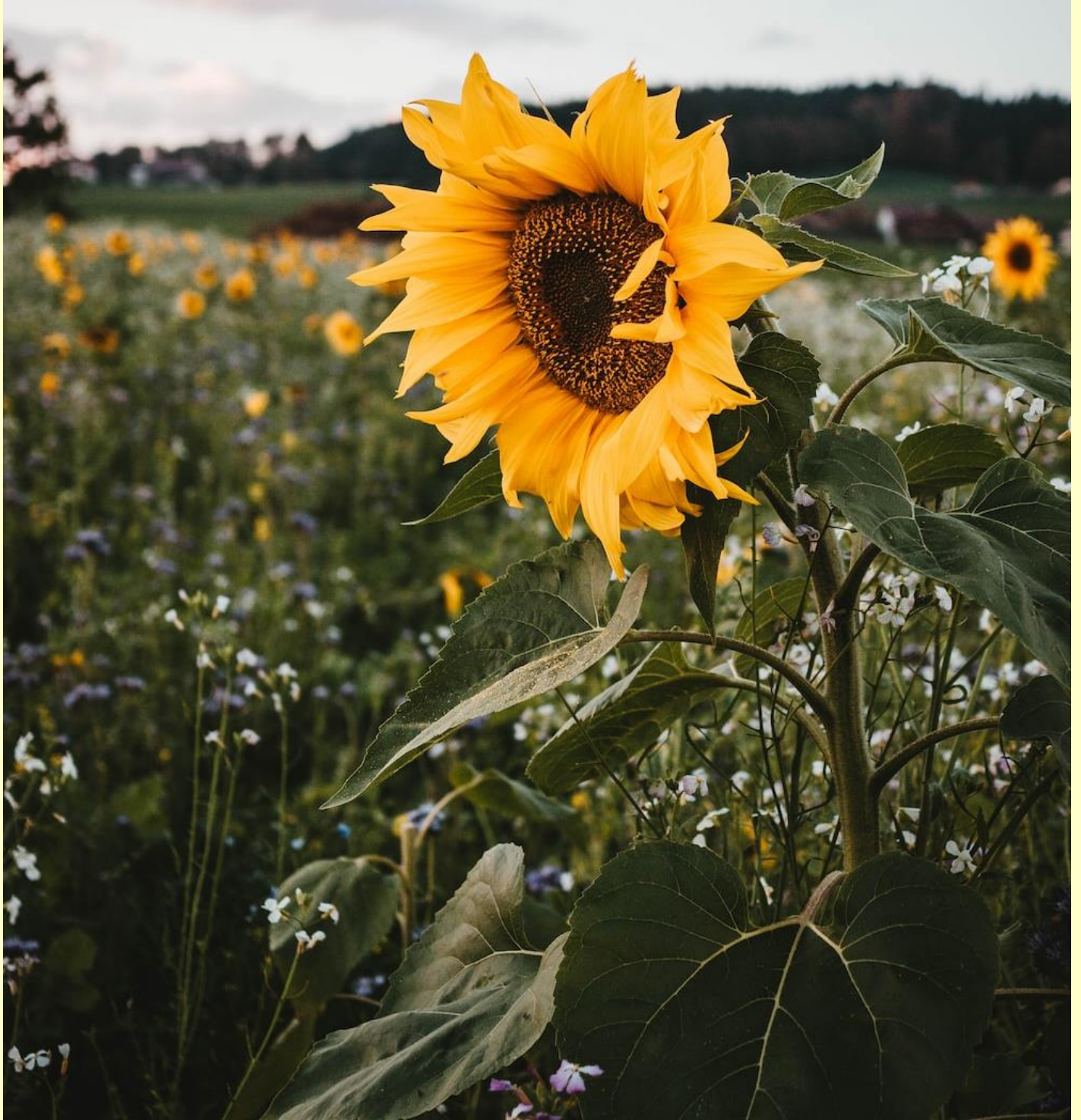


**Love, Care &
Dignity in Dying**



To Improve Hospice Care at Home

Thoughts from a family for professionals, people and families living with cancer

This personal story may help those involved after a diagnosis of terminal cancer and lead to improvements in the provision of cancer care. It is written from our experience of caring for Shaun - husband to Teresa and brother to Sharon - over an 18-month period from March 2021 to 20th September 2022 when Shaun passed away.

We start with how Shaun's diagnosis came about and his first treatment. After this we describe three key aspects of Shaun's experience: diet and eating, pain management and his end-of-life crises. These highlight the nature of the suffering he went through, the added cruelty in losing his ability to eat and lack of joined up care in providing 'hospice care at home'.

We appreciate the support and care from the health professionals involved with us. We believe changes are needed to the system of care and recommendations are given at the end of this booklet.

In our experience of looking after Shaun at home there was a lack of communication between health professionals. We never found out who held his care plan and managed his care. Shaun only heard from those providing immediate treatments, as he the patient, had to ask for help rather than there being a pro-active team to steer Shaun's journey with cancer: a team that would prepare Shaun for the physiological and psychological trauma ahead and provide him and family with the range of support we would need.

Shaun did not want to burden anyone. He carried on working for as long as possible. Although he rarely asked for help, he sought a second opinion and persistently pursued treatment with zoledronic acid. This drug maintains the integrity of bones as they are attacked by secondary bone cancer. He fought for life, worked and laughed, and made the most of his time with family. But his quality of life was hit hard by lack of preparation and support for hospice care at home.

The beginnings

The diagnosis made in April 2021 was unexpected. Shaun suffered with chronic back pain. A year earlier Shaun saw his doctor because the pain was different and he felt something had moved in his back. The view of the doctor was that this was his normal pain and Shaun would be referred for physiotherapy if it was still a problem in six weeks. Over the coming months the back pain continued but Shaun took the expert view of the doctor that there was nothing unusual in this pain.

This normalisation of back pain, it being taken for granted, and that there is nothing to be done is the first issue we share. We believe the patient seeking help should be listened to and chronic conditions should not be taken lightly. Conditions change. We wonder whether this response is a one-off or are others suffering with chronic pain treated similarly?

A year later, on passing blood in his urine Shaun called the NHS 111 service. It took 5 calls and 30 hours to get a response. Throughout Shaun's illness we had problems when we called 111 for help, we'll share these later.

Following the 111 calls, Shaun and Teresa attended his GP, then to hospital where he had scans. In April 2021, they met with a cancer consultant to be told Shaun had stage 4 renal cancer with secondary bone cancer in hips, knees, around the ribs and spine. It was incurable. They met with the Macmillan nurses. Shaun was told he would have a team involving a range of health professionals looking after his needs. In the months that followed there seemed no central point of contact. The only contact was with the consultant and those dealing directly with his cancer treatment therapy.

Shaun was remarkable in how he dealt with the diagnosis. Like others living with terminal cancer, he decided to try treatments. Stage 4 renal cancer patients may have up to three 'lines' of drug treatment on the NHS. For many, the first is considered the most effective. Shaun's first line was a combined treatment of immunotherapy and chemotherapy that he started around May 2021. He carried on working and treated every day with humour and love for life. He loved food, gardening and nature. He grew food and cooked from scratch with scores of spices from different cultures. Shaun looked and felt well and had bought a T shirt that said 'living with cancer'.

But the first line treatment was not successful for him. This was a terrible disappointment. Shaun decided for a second opinion from a renal cancer

specialist and hoped to have access to trials and second line treatment. Shaun's renal status was too poor to take part in the trials. By November 2021 he started his second line treatment, a chemotherapy drug called cabozantinib. Over these months, he retained his sense of humour and would cry with laughter to 'Only Fools and Horses', and sing with passion to Bowie and U2.

Food, drugs and weight

Shaun was around 1.67m in height and 84 kg in weight with a body mass index around 30; within the obese classification. As a dietitian, I was aware of the need to maintain nutritional wellbeing throughout illness and the potential adverse impacts of drugs on eating. Shaun had brilliant creative cooking skills and knowledge and was conscious of the need to keep up his nutrition. I was in regular contact with Shaun and often asked about his eating habits. In September I noticed he was losing weight and independently, I reached out to specialist cancer dietitians for help to see how could my brother be referred to their service. It was disappointing that I had no response. At that time, Shaun and Teresa were not majorly worried about weight loss because the cancer specialist doctors did not seem concerned. In hindsight, this should have been a concern. As we learned Shaun's excess fat likely added months to his life because this provided him with energy reserves that he used when his eating capacity was destroyed through his drug therapy. It's called the 'obesity paradox'.

Shaun's eating was impacted by several things including having extensive dental work that was required to commence the zoledronic acid. But the greatest impact was through cabozantinib.

Within a few weeks of starting cabozantinib Shaun's taste and texture sensors were destroyed. Shaun still had an appetite and wanted to eat. He loved food. He loved cooking. It was an added cruelty that he lost his ability to eat. Everything tasted like dirt and felt like sand or cardboard in his mouth. We ordered supplements. Shaun couldn't tolerate any of these except one mild apple flavoured juice. For a while he couldn't tolerate the smell of food cooking. Throughout his illness he only tolerated that one mild apple flavoured juice but managing no more than one and a half a day: 450 calories. He managed ice cream sodas made with coke and ice cream, and milky coffee, maybe another 600 calories.

We sought help from a specialist dietitian who met online with me and Teresa, who was very sympathetic and helpful with ideas and supplements. We were introduced to Ryan Riley's cooking techniques for people living with cancer and taste dysfunction. It focused on stimulating the trigeminal nerve. Shaun tried these recipes but the experiment failed. The fall-back position was to continue supplements and eat what he could. Shaun understood more than we did just how far backwards his capacity to eat had gone and he calmly tolerated our efforts. Shaun's ability to eat never recovered from the cabozantinib. He continued to lose weight. Over the following months Teresa and I had a few online meetings with dietitians. There was nothing more to be done other than continue oral nutritional supplements and encourage small amounts of nourishing foods. Maybe some home visits to meet Shaun and assess his needs and capacity to eat might have helped. Could PEG feeding have been considered (tube feeding through the skin and the stomach wall). Shaun wanted to live as long as possible and likely would have agreed to PEG if discussed early on.

Shaun was told in December that the cabozantinib was not working - but to be sure, they wanted to continue for a short time longer. Shaun wanted to eat christmas dinner with the family, so the consultant gave him a short break from the cabozantinib. They thought his taste buds would recover in 5 days. That wasn't the case. Shaun's expectations were raised but he couldn't eat. Teresa found him crying in the bedroom alone. He didn't want to spoil our Christmas by seeing his terrible sorrow.

Most days Teresa sat alone at the table. She felt terrible guilt that she cooked and ate yet Shaun couldn't eat. Shaun took himself off the cabozantinib a few weeks earlier than the doctors knew. His taste never recovered. He tolerated at best one to two mild apple flavoured supplements a day, and managed the ice cream soda. We fortified the food he did manage for example, making ice-cream with a supplement high in nutrition, and fortified fresh juices with glucose powder but Shaun couldn't accept the taste. As weeks went by, he tried small amounts from Teresa's plate. He instructed Teresa how to make a wonderful lamb casserole for family and friends. He couldn't eat it. He ordered middle eastern takeaways for us but he couldn't eat more than the smallest amounts. We sought dietetic help and received caring responses but it was disconnected from my brother's inability to eat. Shaun had not talked with the dietitians and felt he had not been prepared for the onslaught the drugs unleashed on his capacity to eat.

Shaun's diet was high in sugar. In November 2021 his mouth was sore and he was checked for oral thrush and was given steroid mouthwash. We don't think he was diagnosed with oral thrush at that time. It possibly was caused by his high sugar, liquid diet. Forewarning that this might happen would have been useful for all of us including Shaun, the patient.

In the summer of 2022, Shaun was given drugs for oral thrush and an appetite stimulant. In many ways - too little too late. He had undergone months of non-eating and disappointment with food. Shaun had no psychological preparation for dealing with the loss of his capacity to eat and possible options to maintain his nutritional wellbeing for as long as possible. Preparing us all in advance would have made a difference.

I asked Shaun whether forewarning of the direct impacts of the drugs and use of supplements might have helped him cope. He did cope because he was fighting for life but the cruelty around food was immense for him. This must be avoided for others. In diabetes-care, families and people living with diabetes have workshops about what to expect and how to cope. This should be offered to people and families living with cancer. We threw out scores of supplements. I tasted them and would find it difficult to live on these as my main source of nutrition.

Returning to Shaun's BMI, which classified him as obese. Shaun's weight went from 84kg in April to 69kg in September 2021, losing a kilo to one and a half kilos a week thereafter. On passing Shaun weighed around 45kg. If his starting point had been 65kg with a BMI of 25 he would have passed away months earlier. The 'team' should be concerned about any weight loss and promote weight maintenance in an effort to maintain patients' quality of life for as long as possible. This was not the case with Shaun. Intention was there but not the practical support.

Pain management and the team

In the summer of 2022, Shaun experienced two crises - one pain and one constipation. Both in the run up to weekends. Help was sought at weekends.

The pain management nurse was due to call on Thursday and was unable to, so rescheduled for Tuesday. On Thursday we called the GP around 10am, we were number 56 in the queue so opted for an automated response which

came at 12.15am. On Friday, a doctor advised us how much morphine to give. On Saturday it was clear Shaun was in a bad pain crisis. We phoned the hospice and despite the label 'hospice care at home' there was no doctor for weekend visits if not in the ward. We phoned 111, were told a GP would visit from the local pharmacy. We phoned the pharmacy who said that wasn't the case. We contacted 111 and eventually a GP phoned us and advised how much oral liquid morphine to give – more than previous advice. In hindsight, a GP should have visited, and a nurse, to give professional guidance on the morphine.

Shaun was in bed and the days melted into each other. Teresa thought we were losing Shaun and we all came to visit. But somehow Shaun pulled through. Teresa said '*I've got my friend back*' when after 7 days Shaun walked into the kitchen. He thought he'd been asleep for a day. He called it 'my morphine fog' and after that was more conscious about how much morphine he had. It was a trade-off between brain and pain.



Shaun, moments after he pulled through his 'morphine fog' when he lost 7 days and Teresa got her friend back.

Soon afterwards Shaun hit another crisis – constipation – a side effect of the morphine. It was very painful. Over the weeks of these crises, he had very little nourishment.

Teresa was on the frontline of Shaun's care managing pain, constipation, nourishment and maintaining love, care and laughter with Shaun, while looking

after herself! We asked who is Shaun's care manager? Who holds his care plan? We never got a straight answer. Care was divided between hospital, hospice and the GP. The dietitians had no connection with the hospice. The system seemed disconnected and Teresa was left to pick up the pieces.

It seems health professionals have high expectations of what loved ones should do to manage end of life care. Of course, because of the deep love within families, we want to take responsibility to provide care. But this must be done as part of team with experts from the health system. Otherwise, the quality of life of the person living with cancer is unduly impacted, family members are left in torment because despite doing the best we can, we are not professionals in end-of-life care.

A few months after Shaun's diagnosis Teresa asked for training in manual handling. Teresa as a teaching assistant, was practiced in sensory work and was able to provide Shaun with gentle, calming touch. She understood that Shaun's mobility would suffer, at some point, because of the secondary bone cancer. So, she looked for the training. It never came. This put additional and unnecessary stress into living with cancer. Shaun loved his baths. On one occasion Shaun could not get himself out of the bath. Teresa was devastated seeing Shaun's loss of dignity and with no manual handling training to help, was terrified she would hurt him. She turned away and cried without Shaun seeing, took a breath turned back and said they would work it out. They did.

The pain assessments do not seem to work well. Scales of 1-10 are not objective and need probing to understand impact on daily activities. If these are affected then the pain is significant. In 2010, the British Pain Society wrote a pamphlet on cancer and pain. They say *'Cancer pain is often under-reported and under-treated for a variety of complex reasons, partly due to a number of beliefs held by patients, families and healthcare professionals'*.

So, patients should not be blamed for not opening up about their pain levels - as some professionals seem to believe.

Building good relationships and trust between health professionals and the patient is critical for dignity and enabling quality of life. One time, when yet another nurse insisted on taking blood in a way that Shaun knew was painful and he again gave advice about how to take his blood in a better way, he became tearful and said *'Why don't people listen to me?'*

The final crisis

In September Shaun hit another crisis. He said he 'felt like he'd fallen off a cliff edge'. I tried to offer help but at that time didn't understand the importance of what he said. Within two weeks he couldn't walk and he couldn't manage even a tiny amount of nourishment. The pain management nurse rescheduled their visit. We called for another. On seeing Shaun they raised the alarm bells. Daily visits followed by GP or hospice and then we called in the crisis team. We learnt about 'the driver' for the morphine and other drugs which is an intravenous device that is set to continuously deliver drugs. In hindsight, this device should have been discussed with Shaun and ready for use much earlier, to ensure his pain was managed calmly rather than the chaos we experienced.

At the start of the cancer Shaun bought a new long leather black settee. It was comfortable for him to lie on. He did not want to spend any time in hospital or in a hospice and did not want a hospital bed. The nurses argued we should get a bed but didn't explain why or what a 'Plan B' would look like if Shaun refused. When Shaun lost his mobility and couldn't be touched because of the level of pain maybe the bed might have helped. But he didn't want the bed so we tried to adapt the settee so he could be supported at an angle and wouldn't fall out of the settee. We had no turning mat - didn't even know of their existence. So nurses manually moved him and the pain was crazy. From then on, at Teresa's insistence, only she would move Shaun. Instead, a Plan B could have been worked out with nurses and an occupational therapist to make the settee safe and minimise Shaun's pain. When it was clear Shaun was staying on the settee and would die there, we moved mattresses into the living room and slept with Shaun so he was never alone.

In his final few days, chaos ensued. The district nurse set up the driver and said it would be monitored to establish the appropriate dose. This entailed us calling the nurses when Shaun was in pain. After the third visit and fourth phone call, their office called us to say we were calling too much!

On fourth visit, the nurse gave Shaun a drug which we were told would 'calm' him. However, he wasn't distressed. In hindsight we believe that the drug was given to prepare for a peaceful passing. We were not aware of drug management for end of life. At 8pm his temperature hit 41 degrees. Teresa tried to cool him and we called the hospice and then the crisis team. They said he needed liquid paracetamol and for the morphine prescription to be increased. This required a GP visit, to be arranged by calling 111. The two of us

were on our phones to different operatives at 111. It was a nightmare. After midnight we spoke with a hospice nurse who explained the temperature reflected his body's system failure and he had only 24/48 hours to live. Eventually at 3am a GP visited and increased the prescription so the nurses could give more morphine.

The next day family visited. Shaun was calm. At 8pm he couldn't breathe. We called the crisis team who told us to turn him onto his side. We called them a third time and 5 minutes before they knocked on the door he'd passed away. Shaun told Teresa if he'd known how bad it would become, he would have 'taken a flight to Switzerland', that is, opted for assisted suicide.

The people involved in our experience were all wonderful and caring. We understand the pressures that are on the health system because of underfunding and shortages. We are grateful for the help we had. However, the 'hospice care at home' system did not work well for us and likely for other families. Often in our gratitude and grief we do not share our experiences but if we do, we can improve the system for others.

Our main lessons are:

- Chronic back pain should not be taken for granted by medical professionals
- Maintaining good nutritional status with no premature weight loss must be understood by all medical professionals, patients and families living with cancer.
- A care plan co-ordinated between the medical professionals and health providers is essential.
- The families should know who holds and manages the care plan and have a copy.
- People and their families living with cancer need training in what to expect and how to manage. For example, a 6-week course covering available support, nutrition, pain, mobility and psychology. Booklets and kind words aren't enough.
- The 111 service is inadequate in providing help in palliative care.

Government agencies

These last thoughts are about the additional issues posed by governmental bodies and, finally, the potential benefits of support groups.

Government non-medical support systems, that is the Department for Work and Pensions (DWP), provide an additional and unnecessary barrier for families to support their loved ones living with cancer. We experienced, gatekeeping of the support rather than facilitating it. This may be unintentional but it increased stress, and induced and exasperated the grief you feel everyday knowing end of life of a loved one is near.

With some experience in dealing with the DWP and other departments and the stress this causes, I volunteered to help with paperwork. First task was applying for Personal Independence Payments (PIP). I was reduced to tears when I saw online a box labelled with the word 'terminal'. It fast tracks the claim but is highly insensitive to ask the newly diagnosed person. People living with a terminal illness are issued a DS1500 certificate, and using this as label for the DWP link would likely be more sensitive to their feelings.

Many conversations were had with the DWP, adult social care and others as we tried to find support. Most were insensitive. It is shocking that people living with terminal illness who are forced to stop work are then reduced to living in poverty while they die. Advice from Macmillan's finance support lines were excellent and the staff were caring. On this advice Teresa applied for the bereavement grant the day Shaun passed because it is not backdated.

Teresa was turned down on the £67 a week carer's allowance because working 13 hours as a teaching assistant on minimum wage took her £6 over the threshold.

It is unimaginable how people cope when living alone with terminal illness. They are thrown into the indignity and stress of poverty as they are losing life itself.

Renal cancer research support groups

We learnt by trial and error that the cancer support groups, with people living with or surviving cancer, can provide very good advice and guidance as the cancer progresses. Shaun wanted to try his best to fight the cancer. The *Action Kidney Cancer* group helped us find specialist second opinions and to look at the possibility of drug trials.

As Shaun said, 50% of the UK population will get cancer at some point in their lives. There are advances in treatment but kidney cancer remains incurable. To help find a breakthrough please make a donation to:

Action Kidney Cancer: <https://actionkidneycancer.org/>



Loving hands with Shaun Patrick Gunning

Aka shaun.sunflower; the singer

Notes

Notes

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To Improve Hospice Care at Home**

Please contact us at

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And a big thank you to Arti Dillon for helping us with our project to improve the quality of life for people living with terminal illness.

<https://lastpictureofyou.org/>