



**NAVIGATING  
THE JOURNEY**  
A GUIDE FOR PATIENTS  
AT PROSPECT HOSPICE

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# WELCOME

Welcome to this booklet which I hope you will find a useful companion. We know you will have many questions at the moment and the team is here to answer those whenever you have them. In the meantime, we've put together some of the common questions we've been asked to help you navigate this journey.

You have been referred to Prospect Hospice so we can support you using our skills, knowledge and expertise to help you live well at this time of your life. Please don't be afraid. We know that many people can be frightened when they speak to the hospice but we're dedicated to supporting you and doing everything we can to help you live your life to the full - whatever that means for you.

My advice at this first stage is to talk to those important to you about how you are feeling. You could be feeling a whole range of emotions at the moment and sharing these really does help. It also helps those who care about you to understand what you need right now. If that all seems too difficult at the moment then please do talk to us.

Over these next few pages you'll find options available to you from us that may help you. Our care is tailored to your individual needs so please do speak to us about what's important to you so we can make sure you're getting everything you need right now. The team will work with you every step of the way and, if your needs change, so will the care and support we offer you to reflect that.

I don't want you to worry about the cost of any of this. Thanks to our generous community which donates their time and money to the hospice, all the care and support you receive from us is free. You can read more about how the community makes this possible on page six.

For now, please take a look through this booklet and, should you have any questions, please do speak with a member of the team next time you see them or contact us via the details in the back of this book.

*Sheila Popert*

**Sheila Popert**  
Medical Director

# ABOUT PROSPECT HOSPICE

## THEN

Since 1980, Prospect Hospice has been part of the community in Swindon and north east Wiltshire, dedicating itself to providing the best end of life care to local people but we've only been able to do that thanks to the support of the community that raised the millions we need each yet to pay for it.

From the very beginning, when Reverend Derryk Evans gathered together a small but strong team of people to bring a hospice to this community, donations from the public have been imperative to enable Prospect Hospice's to not only survive but thrive.

Thanks to local people giving their skills and time, and some initial funding from people and businesses, the then Prospect Foundation was established in 1980. Initially operating a two-nurse, home-based nursing service, as our reputation grew and the demand for our care increased, we found a base at the Victoria Hospital in Swindon's Old Town, which is now apartments on Okus Road.

The more people whose lives were touched by our care, the more people began to show their appreciation of our work.

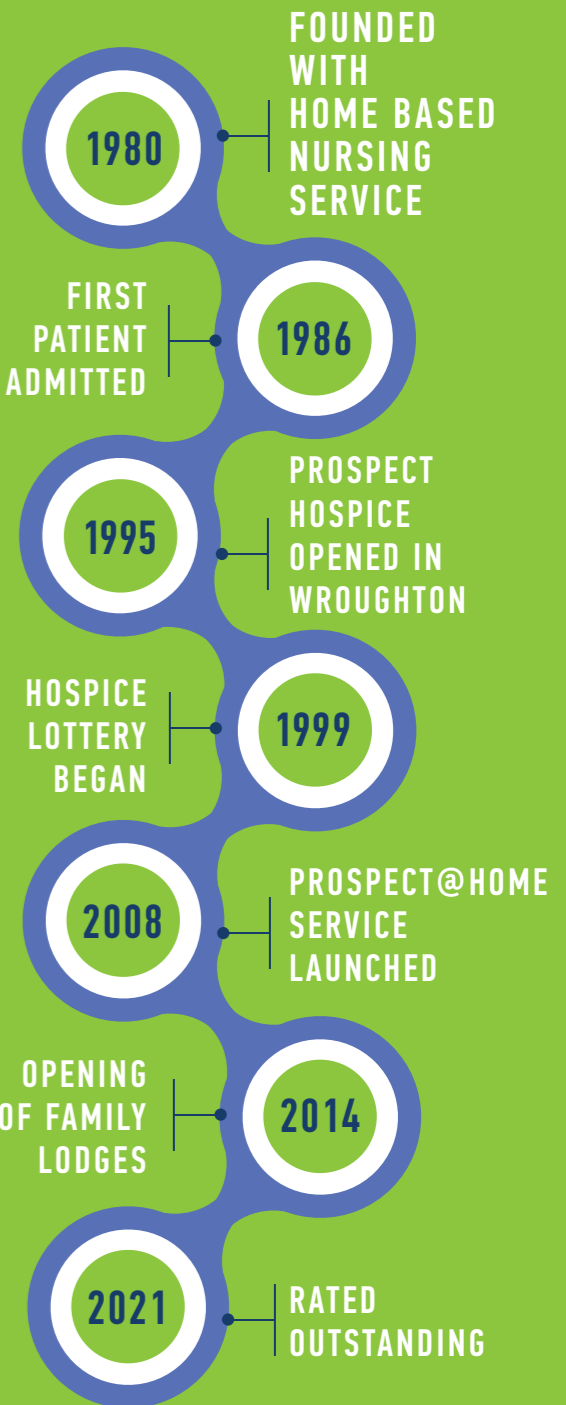
As Prospect Hospice moved into a second decade, we needed new premises, and launched a community appeal, led by our late honorary president David Margesson MBE, for a purpose-built hospice that would become a permanent base. The appeal to raise the £3 million needed to build the hospice achieved its target in 1995 and, later that year, Princess Anne officially opened the new Prospect Hospice. More than two decades later, we're still using that same building in Wroughton as a base for our clinical teams.

## NOW

**Our specialist teams of nurses, doctors, physiotherapists and healthcare assistants are highly skilled and experienced in caring for patients with complex needs to help them live with a terminal illness and, when the time comes, to ensure that people experience a dignified death.**

Our latest inspection by our regulators The Care Quality Commission rated us as 'outstanding' and recognised how our care teams ensure our patients are active partners in their care and feel they are truly cared for and supported by hospice staff. What matters most to us is knowing what matters to you. We pride ourselves on working with those in our care to understand what's important to them so that we can tailor any care we deliver to their personal needs.

Prospect Hospice is a registered charity and the local community raises millions each year to fund all the services we're able to offer free of any charge to our patients and their families.



# HOW YOUR CARE IS FUNDED

Often when we hear something is free, we ask what the catch is. We can promise you there's no catch here. From the very moment we start to support you, we want you to know that there will be no bill for the care you receive from us for you or your family to worry about. Everything we offer you is delivered free of charge.

We do obviously have to fund this somehow and that's done through the generous support of the local community. Yes, all those people organising bake sales, playing our lottery and jumping out of planes to raise money really does add up and, between everyone, they raise around £5.5million a year to help us deliver the care you will receive, alongside around £2million that we receive from statutory funding – money given to us from the government, such as the NHS.

We also have an army of around 700 volunteers who dedicate their time to helping us deliver care. You may see some of them if you're in the hospice or they may come to your home. They also assist us in our shops and help raise over £1million a year for the hospice. In fact, you'll



find our volunteers almost anywhere we are, ensuring that we can continue to offer our care to all that need us.

If you or someone you know would like to know more about how they can support our work, please visit [www.prospect-hospice.net](http://www.prospect-hospice.net) for more information, or contact our fundraising or volunteer teams directly – you'll find their details in the back of this book.

## DO YOU HAVE PRIVATE HEALTH INSURANCE?

Did you know that if you have private medical insurance the hospice may be able to recover some or all of the cost of your care from them, with no cost to you? Please let one of our team know that you have private medical insurance and we can work with you and your provider to look into this further.

# YOUR REFERRAL

You are receiving this booklet because you have been referred to the hospice from someone who thinks you can benefit from our support and, by now, you will have spoken to a member of our team who has sent you this booklet to let you know a little more about how we may be able to support you. You may not need everything mentioned here but it gives you an idea of what is available to you, and those important to you, should you need it.

## So what's next?

Firstly, we want you to know that you are not on your own. We're here to support you with whatever you need, whenever you need it. That may be now, in a few weeks or even years down the line.

A member of our team will soon carry out a telephone consultation with you and explain the next steps. You are welcome to involve anyone in this consultation that is important to you.

During this conversation, together we will complete an assessment to discuss your needs and concerns to help us to ascertain what matters most to you, how we can best support

you, ensuring you receive the right care at the right time, and introduce you to those who will be involved in your care. We will also establish with you your preferred choice of communication (which may include telephone support, video consultation, or face to face contact) and identify if you have any communication difficulties or preferences.

Should you have any questions before your consultation, please do give our single point of contact (SpOC) team a call. You'll find their number the number in the directory at the back of this book.

## DO I NEED TO PREPARE ANYTHING BEFOREHAND?

No. The assessment will take the form of a conversation. Much of this will be about how you feel along with discussing your wants and needs but if we need any further information, we can gather this later.

Before we chat, it may be worth completing the diagram on pages 10 and 11 as this will help you to start thinking about what's important to you at this time.

# YOUR QUESTIONS ANSWERED

Across these two pages, we want to try and answer some questions you may have or address some thoughts you might be having at the moment. If you have any other questions, please speak to a member of the team who will be happy to answer and you can note these down on the back cover so you have them ready.

## What is palliative care?

You may have heard the term 'palliative care' recently and may be asking what this means. Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. The aim of palliative care is to enhance your quality of life and help you maintain your independence.

Palliative care can help reduce symptoms of your illness, which may include pain, fatigue, nausea and constipation, and can reduce side effects from treatments and medications.

The role of palliative care is to:

- help you achieve the best quality of life
- make sure your physical, practical, emotional and spiritual needs are met
- help you make decisions about your treatment and ongoing care

Whatever stage you're at, our team will continually assess your changing needs and adjust your care to suit you.

## What is symptom control?

Our nurses, doctors and therapists work with you, and the people who are already treating you, to find support, treatments or medicines that can help you live fully. We will keep in touch in a way that suits you to make sure your

symptoms are being managed properly, and offer advice to other doctors and nurses who are helping you.

## I want to be as independent as possible, can you help?

Our team will talk with you about what matters most; this could be anything from keeping your strength up so you can spend time with children or grandchildren, to help with making a cup of tea, or even talking through what death could look like at home.

We'll then work with you to come up with ways to help you achieve what you want from day to day and this could involve personalised exercise plans, new equipment or reviewing the activities you do each day.

We can also help your relatives and friends understand how your illness might affect you, and help them be there for you.

## I feel anxious most of the time, can you help?

We know that mental and spiritual wellbeing is just as important as controlling physical symptoms, both for a person with a life limiting illness and the people closest to them. All of our staff are able to offer support and our family support team can offer counselling and advice, as well as spiritual and religious support for you and those close to you. All sessions are confidential and many say that they use what they have learnt from our team to help other family and friends.

## I am worried about my financial situation, can you offer support?

We will never charge you for the care we provide but, for some, other costs and lost income caused by a life limiting illness can be worrying. Our team can help you with applying for government funding that you might not even realise you are entitled to.

## Can I make choices about my care?

Yes. Shared decision making is important to us and we'll always discuss care plans and suggested treatments with you (and your relatives if you wish).

You may wish to make some decisions about your future care and treatment and making

an advance care plan is one way to do this. An advance care plan provides a useful framework to help you, either independently, with your family and friends, or with the help of staff, to think ahead, outline your preferences and state any special wishes or concerns regarding your future care. This is particularly helpful if there's a time when you might be unable to explain these easily for yourself.

# WHAT MATTERS TO ME

The support offered by Prospect Hospice is tailored to your individual needs so you receive the best support possible. It's therefore important for us to know what matters to you. This could be anything from wanting your family to be kept informed or that you'd like your dog to be with you when you die. Whatever matters to you matters to us and we'd like to know what this is so we can do what we can to support you.

Please use the diagram opposite to write down those things that are important to you. There are eight spots but you don't have to fill them all. Likewise, if you have more, please jot these down in the blank space below.

A large white rectangular area with rounded corners, containing ten horizontal blue lines for writing.



# HOW YOUR LIFE MAY CHANGE

Living with a life limiting or terminal illness and not knowing what the future holds can be overwhelming and upsetting. You may be wondering how your life may change, what happens with your work, managing your affairs, what symptoms you may develop and you may have questions about what medications you are being given.

We're here to help you manage all these thoughts and feelings but it's important to know that everyone's experience of this is unique and there's no right or wrong way to feel.

It may be useful to use the space below to note down how you're feeling at the moment so you can discuss this with a member of our team next time you speak to them.

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# COLLEEN'S STORY

**Eighty five-year-old Colleen Maskell has loved being on the go all her life. Raised and educated in India, she married at 18 and within a few years was mum to three young children. She and the family moved to Liverpool, and before the first week was out she had landed a job on the assembly line in a factory.**

Her husband had always worked on the railways in India, so it's not surprising that they eventually made their way to Swindon for work. Colleen worked in retail, accounts, became an usher at Swindon Court and worked for Meals on Wheels on retirement.

So when she began to feel unaccountably exhausted and found some lumps behind her ear, she went to her GP. The diagnosis of lymphoma was shocking, but Colleen says the great faith she has in God helped carry her through the initial tests and some treatment. She declined some of the more invasive treatments that were proposed, and decided she wanted to live the rest of her life as normally as possible.

Colleen's spirits began to dip when she realised that, despite wanting to do this, she had

simply become too tired and weak to even start.

"Fortunately, I had been put in touch with Prospect Hospice by the hospital, and the nurses there kept a close eye on me," says Colleen.

"One, Sarah, suggested I go into the hospice's inpatient unit, so that they could help me rest and get my energy levels back up. And it was absolutely fantastic there.

"I had a beautiful room to myself, and it felt like a posh hotel. I didn't have to worry about anything and the staff were all so kind to me.

"I really hadn't known what to expect before I went in, but every single person there was kind, attentive, and so caring. They really do love their patients. When I came to go home a few weeks later, even the chef came to say

goodbye to me."

Colleen says the "recharge" she got during her stay at Prospect Hospice enabled her to carry on living life "her way" for far longer than would have otherwise been possible. What surprised her, though, was that she was not charged a penny for the care she received.

"The quality of care is so high, and there's such expertise, it's incredible that there is no charge to patients or their families. It's the people who give to Prospect Hospice, do fund-raisers, buy lottery tickets and help in other ways that keep Prospect Hospice going. We are so lucky to have the hospice. You never know when it could be you that needs it - and as someone who has needed it, I can't thank those who support it enough.

# SUPPORT FOR YOU IN YOUR HOME

As we discuss the options available to you, you may decide you want to spend the end of your life at home, in familiar surroundings, with the ones you love by your side. If this is the option you choose, we have plenty of support available to you to help with this and have dedicated teams to help you with a range of things to make your home environment more comfortable for you at this time.



## LINDA'S STORY



**Sometimes it can be the little things that make the difference between coping with a life-limiting illness and feeling overwhelmed.**

**When Linda Davis, who lives in Penhill, was caring for her partner she found the Carers Café at Prospect Hospice a lifeline.**

"Caring for someone can be exhausting, and being able to sit down with a cup of tea and talk to other people in the same situation helped so much," says Linda. And there were talks after each café session where you all learned more about the journey you're all on where you can ask questions. That really helped too."

But after the loss of her partner, Linda was to face more tough times. She fell and broke her hip badly and, while she was being treated, scans showed that she had lung cancer, and it was terminal.

"I'd been having bereavement counselling from Prospect Hospice, which helped so much, but now I had another reason to need support from them," says Linda, who is 65-years-old.

"My daughter, Clare, her husband and their four children had moved in with me temporarily, and Clare became my carer. But there were practical problems – because of my broken hip I had to sleep downstairs in the utility room, and space is limited in there so I needed a short bed.

Prospect Hospice was marvellous in sorting out the practical things I needed and arranged for me to have a short hospital bed and a new wheelchair, fitted with special supports. That meant I could not only get out of bed, but also get comfortable in the wheelchair so I could sit in the front room and even go out to Coate Water with Clare.

It has also meant that I can remain in my own home, which is what I want."

Daughter Clare Baker says Prospect Hospice's single point of contact team has freed her up from administrative tasks like chasing prescriptions or trying to get through to call centres, and allowed her to get on with what she wants to do – give her mum the loving care she deserves.

"In the beginning I could spend hours on the phone, trying to get hold of medicines or physiotherapy or the surgery.

But once Prospect Hospice got involved, everything was smooth. All I have to do is call them and I know that whatever we need will be sorted quickly, often the same day.

Now I can do what I want to do – focus on being a proper carer for my mum."



# CARE AT THE HOSPICE

The hospice has options for you to be in a single room on your own or in a larger room with up to three other people so you can chat to each other. Whichever option you think will suit you best is the one we'll try our hardest to accommodate. The majority of our rooms also have their own access to our beautiful gardens where you can enjoy a walk with family or simply sit out in the fresh air.



# KEVIN'S STORY

**Maureen King loved her job at the Royal Mail in Swindon, but not long after being diagnosed with motor neuron disease in 2016 she had to stop work. She was becoming breathless, and anxiety about her future meant she slept poorly. Her husband, Kevin, soon became her full-time carer.**

Kevin says that the various types of support they were given by Prospect Hospice improved the quality of both their lives considerably.

"Maureen was on oxygen and she used to get very panicky and agitated," said Kevin.

"Her biggest fear was that she could choke to death. The Prospect Hospice therapists visited her at home and spent time with her. The breathing techniques they taught her really helped to keep her calm."

Maureen also attended day therapy sessions at the hospice where she enjoyed taking part in different activities and meeting other people who were experiencing similar illnesses.

Maureen also benefited from a class at the hospice which taught techniques to help with sleeping. During her illness Maureen stayed

in the hospice's inpatient unit on three occasions, including in June 2018 when she celebrated their son's birthday.

"Maureen loved her kids and grandkids - they were her life, along with me. When she was staying in the hospice for respite care it was our eldest son's birthday and the staff encouraged us to have our son's party there.

"We had it in the garden outside the inpatient unit and the staff took Maureen there in her bed. Maureen absolutely loved it and couldn't stop talking about it. It is a really special memory."

Maureen and Kevin were also supported by the hospice's social workers, who helped Kevin to access benefits he was entitled to.

"They were absolutely fantastic. They visited us at home and helped us with anything they could. They were always there if

we had a problem or needed help with anything," said Kevin.

Sadly, Maureen died in May 2019, aged 60, after contracting pneumonia.

Kevin, who was married to Maureen for 37 years, was so thankful for the outstanding care given by the hospice that he volunteers with the charity in the retail team as a van driver. He joined it three months after Maureen died and volunteers five full days a week.

"Being a volunteer at Prospect Hospice is the best 'job' I've ever had," he said. "I enjoy it and I just felt I had to give something back to thank them for caring for my wife. By volunteering I'm helping to spread the word about the hospice and I'm helping it to raise the funds it needs."

# WHAT TO EXPECT WHEN YOU ARE DYING

Thinking about your own death can be scary but we're often asked what people should expect. Below you'll find some information which can also be found in our 'understanding what happens when someone is dying' leaflet which you may find helpful.

Thinking about the last hours of someone's life can be hard, but knowing what to expect may make things a little easier.

## Eating and drinking less

When dying, people don't need the same amount of food and drink as before, because their bodies can't digest or absorb it. Accepting this can be hard, as we instinctively want to nourish our loved ones.

Withdrawing from food and drink is a natural part of dying. You can help by moistening the person's mouth with swabs or lip salve.

## Withdrawing from the world

People withdraw from the world gradually. They may sleep more, become weaker, or appear to lose interest in their loved ones and surroundings.

Withdrawing from the world is part of the dying process. But it's natural to find it upsetting and frightening. Being there for someone, holding their hand or speaking quietly to them can be very comforting. Even if the person is unconscious, they may still hear you or feel your presence.

## Becoming restless or confused

Some people become restless or confused as death approaches. For example, they may see or say things that don't make sense. As well as keeping pain and other symptoms under control, the doctors and nurses can alleviate restlessness with medication.

Knowing you're by their side can help the person. You may want to talk to them, hold their hand or play their favourite music to help them relax.

## Breathing changes

People's breathing can change as they near death. That's because their bodies are less active and need less oxygen. You might notice longer gaps between breaths, or irregular and shallow breathing. Sometimes in the final stages, breathing can become noisy due to fluids building up in the back of the mouth or throat.

Medication and changing the person's position can help, but while this noisy breathing might be upsetting for you, it doesn't usually distress the dying person.

## The final moments

Before dying, a person's skin can become pale, moist, mottled and slightly cool. Their face and body may relax. Their eyes may become less clear and they may become very pale. Eventually, their breathing will stop. Sometimes, there is a gasp a few minutes after what seemed to be the last breath.

You may find it reassuring to know that most people fall asleep and then die peacefully and comfortably.

## We're here for you

We know how difficult this time can be. If you are anxious or concerned about the dying process, you can ask a member of staff to be with you and your loved ones when the time comes.

Please do come and talk to the team. Ask questions, discuss your concerns and don't be afraid to ask for support.

# WHAT SUPPORT IS AVAILABLE TO MY FAMILY?

**At Prospect Hospice, we're also here for those important to you too.**

**When you near the end of your life, there are options available to you and our dedicated team members can support your carers and help them apply for benefits that you and they may be entitled to. They're also able to offer bereavement care and support them through the changing circumstances.**

**Coping with the death of a loved one is incredibly difficult for people and we'll be here after you die to support them as they need.**



"He was diagnosed with cancer in January 2017, and in June that year he was told it was terminal. Ellie and he wanted to marry and he wanted to die at home, and with Prospect Hospice's support both those things happened," says Brenda.

Danny spent some time in Prospect Hospice's inpatient unit and the staff there made sure they could get married in the register office on 1 September and spend their first night as a married couple together in an hotel. After that, Prospect Hospice staff pushed two beds together in a room in the inpatient unit so Ellie and Danny could spend a few nights together there too - they were brilliant.

Once Danny was stabilised, he was able to go back home and Ellie and I looked after him. He did have several trips back to the hospice because they were the only ones who could sort out his

# BRENDA'S STORY

**Brenda Leddy says that after her son, Danny, was diagnosed with terminal cancer at the age of 34 she and his partner, Ellie, did all they could to make his last year as normal and happy as it could be.**

pain relief properly, but we were all so glad he could be at home as he wanted."

Danny died at home on 19 December 2017.

"It was devastating for us all. As much as I thought I'd be OK, I felt absolutely overwhelmed. You can't understand how it feels to lose someone you've carried for nine months and given birth to. For the first year after his death I kept telling myself, you can get through this. But I wasn't okay at all. I was drowning in sorrow. I wanted to die.

Then in February 2019 I met Louise from the Prospect Hospice bereavement team.

Without intervention from Louise my marriage would be over. My husband is not Danny's father, and in my grief I said some things which were difficult for him to hear, saying things like 'it's not your son, how would you know?'

Louise explained some issues couldn't be solved and suggested putting them in a box, putting the lid on and leaving them there. I did this and it saved our marriage and my sanity.

The longevity of the bereavement service is amazing but Louise found a way to make it even better by forming the 'Mums' Group', a brilliant idea and a godsend. I am pleased to say this is ongoing.

I will be so grateful for the rest of my life that Louise and I met. I am no longer on antidepressants and I can now live with the newer version of myself, without my son. I never thought I would ever be able to say those words.

I still have peace of mind that, should I need support at a later stage, I can call on the hospice bereavement team again. Our community is so, so lucky to have Prospect Hospice in our midst."

# YOUR FEEDBACK

Your feedback is incredibly important to us and it helps shape the services we can offer you and others in our community.

To share your feedback about the care you've received from Prospect Hospice, please ask a member of the team for a form to complete, visit [www.prospect-hospice.net/feedback](http://www.prospect-hospice.net/feedback) or scan the QR code below.



Your feedback is always welcomed however you choose to send it to us but please do also speak to a member of our staff at any time if you wish to share a compliment or raise a concern.

# GET IN TOUCH

## Contacting the hospice

Should you need to speak to a member of our team about your care or have a question about how you are feeling, please get in touch with our single point of contact team (SPoC) in the first instance who will be able to direct you call to the most appropriate person. This number can also be used by your loved ones if they have any questions about how we're supporting you.

## Other useful contact details

**Main reception:** 01793 813355

**Single point of contact (SPoC):** 01793 816124

**24 hour advice line:** 01793 816109

**Fundraising:** 01793 816161

**E:** [fundraisingandevents@prospect-hospice.net](mailto:fundraisingandevents@prospect-hospice.net)

**Volunteer services:** 01793 816193

**E:** [volunteering@prospect-hospice.net](mailto:volunteering@prospect-hospice.net)

**Website:** [www.prospect-hospice.net](http://www.prospect-hospice.net)

You'll also find us on social media including Facebook, Twitter, Instagram, LinkedIn and YouTube. Just search for Prospect Hospice.

