

Patient Guide

www.stpetershospice.org



St Peter's Hospice

Registered Charity No. 269177

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Welcome to St Peter's Hospice

Now that you have been referred to St Peters Hospice, and accepted the offer of our care, we will endeavour to do our very best to look after you in every possible way, you and your family.

St Peter's Hospice is a charity providing free care for those with complicated needs often towards the end of life but nearly always needing relief from distressing symptoms or worry's. We provide this care to the people of Bristol, South Gloucestershire, North Somerset and part of BANES.

Our care is aimed at being the very best of health and social care, alongside our healthcare partners, (your GP, local hospitals and District Nurses etc).

To do this we aim to:

- Respond to your needs, preferences and expectations;
- Promote high standards of care both directly and indirectly through education not only to you but also to our own staff, volunteers, the public and the staff of our local care community;
- Meet National Guidelines (such as those provided by the NHS);
- Be responsive to the Care Quality Commission, who ensure we provide care of the highest quality.

We have many services at the Hospice in Brentry but also provide many hours of care by telephone, in the community and in the homes of our patients. Please use this booklet to make yourselves familiar with those you may meet along the journey and also feel free to visit us at Brentry for an informal look around. We have a coffee shop offering visitors and family members somewhere to relax in our lovely environment so please make full use of it!



Sandie Foxall-Smith
Chief Executive



Referral

Who is eligible for our care?

- Anyone over the age of 18 with an active and advanced life limiting disease such as cancer, heart and/or lung disease and neurological diseases.
- Patients referred to us may be close to the end of active treatment when a doctor has advised either that no further treatment will be of benefit or that further treatment is purely for the relief of difficult symptoms.
- Patients may be near the end of their life and may have chosen to die in the hospice. The patient (or their chosen representative i.e. next of kin) must agree to the referral.

Who can make a referral to St Peter's Hospice?

Anyone can make a referral but usually patients are referred by a health or social care professional such as their GP, District Nurse or Hospital Palliative Care Team, for example. The patient's GP must be in agreement with the referral.

Once a patient has been accepted by the Hospice they will be contacted to let them know what will happen next. For the majority of patients the first contact they will receive will be a telephone call from a **triage** nurse. The triage nurse liaises with patients when they are first referred, to introduce the service and assess any urgent issues. This will often be followed by a visit from a Community Nurse Specialist or perhaps an invitation to an outpatient appointment.

Community care

One of the first professionals from the Hospice you will meet will be one of our Community Nurse Specialists.

Community Nurse Specialist Team (CNS)

- The CNS team offer community visits to all patients referred (and accepted) to the hospice services for community intervention.
- They work within geographical areas and we have named staff allocated to specific GP practices.
- Each team member has considerable experience alongside specialist qualifications and training to deliver specialist palliative care advice and support.



- The CNS team works very closely with the Primary Health Care Teams (GP's and District Nurses) as well as the acute hospital palliative care teams (e.g. at UBHT) to provide on-going, seamless support for patients and carers.
- The CNS team aim to enhance the quality of life for all patients by offering specialist symptom control, psychological support, family support, close liaison and support to the GP and DN teams and (if wanted) education.
- The CNS team work very closely with the wider hospice teams to ensure that all levels of hospice services are utilised appropriately to meet the patient's needs. They meet each week with one of our consultants to talk through their patients and identify further input that might be helpful. Our CNS's are often asked if they are MacMillan Nurses. The simple answer is 'no' as we do not receive funding from MacMillan, or any other charity, but they do exactly the same job.



Hospice at Home service

- Our Hospice at Home service provides hands on nursing care to patients and carers in their own home.
- Levels of input are determined by patient need, for example:
 1. Full 24 hour cover during the last week of life, broken down to three shift patterns;
 2. Respite shifts (am, pm or overnight) to support carers who are caring for a patient at home;
 3. Shifts to aid the smooth discharge from hospital or to hold a patient at home whilst awaiting admission to the hospice.
- Care is provided by both qualified nurses and healthcare assistants.
- The Hospice at Home team are supported out of hours by the CNS team (on call) and the hospice advice line.
- Please note that nurses working in patients' homes need to do so in a smoke-free environment.



At the hospice

Day Hospice

Day Hospice aims to provide a therapeutic environment, enabling you to have an increased sense of confidence and empowerment to support you in living with your illness. It is run by a small team of experienced nurses and a doctor.

Patients referred will attend one day a week for 12 weeks; normally arriving for 10am and leaving at 3pm.

Our aim is to provide:

- An enjoyable day, with you feeling supported by both professional staff, volunteers and the shared experiences of other patients;
- Nurses and doctors who will offer advice on symptoms that may be troubling you;
- Individualised care with access to a wide team with many specialised skills – e.g. physiotherapists, social workers;
- The opportunity to learn relaxation skills and participate in gentle exercise;
- Informal discussion groups looking at issues relevant to you as the patients, such as nutrition, planning for the future, understanding and managing medicines, etc;



- The opportunity to receive complimentary therapies such as massage and reflexology;
- Diversional activities for those who enjoy arts and crafts, such as painting, card and jewellery making.

For those who have no access to transport we can offer volunteer drivers. You need to be able to get in and out of a car independently.

A review of your care happens all the time but most patients leave Day Hospice after about 12 weeks.

Fatigue and Breathlessness Management Course

At St Peters Hospice, we run a six week course to enable you to manage your fatigue and breathlessness more effectively and so regain a sense of control.

Each week we will focus on a different area of your life such as energy levels, exercise, nutrition, sleep, breathing control and relaxation.

The course is run by a physiotherapist, occupational therapist and a nurse. The sessions last for two hours and are normally held on a Tuesday morning. For more details, please discuss with your Community Nurse Specialist.

Carers Group

The Carers Group offers your 'carer' (often this is your partner or spouse but it can be anyone you nominate) an opportunity to meet up with other carers for informal support, and discuss issues relating to caring for a loved one. It is facilitated by a nurse and a social worker who can offer advice and information.

The group lasts for two hours, and runs for six consecutive weeks, usually on a Tuesday afternoon. For more information please discuss with your Community Nurse Specialist.

Inpatient Unit

On the inpatient unit our team of skilled nurses and our consultant-led team of doctors work together to provide specialist, intensive symptom control for patients. They also involve all the other members of the wider hospice team in delivering the total care we offer to patients, family members and carers. Admission requests from our community nurse specialists, GPs or hospital colleagues are discussed every morning at a meeting on the inpatient unit, and planned based on the urgency and complexity of patients' needs. This means that some patients may wait for a few days before a bed is available – even though we admit every day. We also respond to urgent requests out-of-hours, and regularly admit patients during weekends and Bank Holidays when this is clearly appropriate and we have a bed available.

Your privacy and dignity is very important to us. There are six single rooms and six double rooms. Wherever possible we endeavour to meet patient privacy needs but



it is not always possible to ensure a single room is available. With the present arrangement of beds we do have to consider each individual priority. It is possible to arrange for any patient who wishes to, to have private conversations when they are sharing a room.

Each bed has a television, DVD and CD player (with no cost for use). Wireless internet access is available so patients can use their laptops.

Any patient admitted will be asked to bring in all the medicines they are taking. This will help the doctor and the nurses to review your problems and make any adjustments.

If patients wish they may bring in their own bedding or comfortable pillows although we always have plenty. Patients can choose to have either blankets or a duvet for their comfort.

There are beautiful gardens to enjoy and even if the patients have to remain in bed we can push the beds outside. For those patients who like to get dressed during the day please ensure you

have a coat and suitable footwear to go outside all times of the year. This wonderful facility is enjoyed by patients, visitors, staff and volunteers together.

Visiting

When you arrive by ambulance you will enter directly onto the Inpatient Unit. All other entries are via the main entrance which is open from 8am to 8pm. There is no restriction to visiting but we would ask that visitors arrive between 11am and 8pm and the team are very pleased to discuss visiting at other times.

Children are very welcome and we have a small range of toys, colouring and games however please could children be supervised at all times for their safety.

Pets can also visit and we would ask that they are kept well under control.

Smoking at Brentry

For those patients that smoke we have a designated area outside of the Unit. Patients can use this facility but for those who are not independently mobile we would ask their friends and family to take them out. We understand that this can be very stressful especially as patients cannot go outside once the building has been alarmed at night. To help any patient with this we have patches and inhalators available. For all others the Hospice is a non smoking facility and we thank you for your cooperation.



Medical

The hospice has a permanent team of 4 senior doctors – the Medical Director, 2 Consultants and an Associate Specialist – who provide specialist medical support to all aspects of our clinical services. They also provide supervision and training for a specialist registrar in Palliative Medicine and for qualified doctors training to be General Practitioners who rotate to the hospice during their training.

The senior doctors are regularly involved in teaching on courses run by the Education Department of the hospice and attending meetings with GP and district nurse colleagues. Both of our consultants also work 1 half-day per week in the Palliative Care Teams at our local hospitals.

Physiotherapy and Occupational Therapy

Our specially trained team work alongside our nursing and medical teams to ensure that physical care and the specialist equipment required for your care is always appropriate.

They also provide:

- Advice to colleagues in the community;
- Advise you when you are discharged home;
- Rehabilitation;
- Assessments of mobility for return home.

Telephone advice line

The hospice also runs a telephone advice line which is available 24/7 every day of the year. Patients and families can use this to seek advice or when they are uncertain about what to do. Healthcare professionals (especially GPs and district nurses) use this service when they need specialist advice. During working hours, calls relating to patients already known to the hospice are dealt with by a professional member of staff who already knows the patient (e.g the community nurse specialist). However there is always a senior hospice doctor available for complex or urgent calls.

At evenings and weekends the call will be taken by one of the nurses on the inpatient unit, who can contact the on-call senior hospice doctor whenever needed.

We keep records of all these calls so we can ensure everyone involved in patient care is aware of the advice that has been given.

24 hour advice line number:
0117 915 9405



To access complementary therapies, music therapy or clinical psychology you will need an internal 'referral' from another member of the Hospice team (e.g. a doctor or community nurse specialist).

Complementary therapies

Complementary therapies are available to our referred patients. They can help you to relax, help with sleep problems and generally help you to feel better about yourself at difficult times.

The team of highly qualified volunteers and one employed complementary therapy coordinator provide therapies such as:

- Aromatherapy;
- Reflexology;
- Massage;
- Indian head massage.



Music therapy

Music therapy can be an integral part of your care at St Peter's Hospice. When you are referred to the Hospice it can be one of the most difficult times for you and your family. Music therapy can help you to express how you are feeling, remember good or not so good times, and express your feelings to someone else.

It is not always for everyone but often worth trying when needed.

Clinical Psychology

St Peter's Hospice has a clinical psychology service that is used to help patients, families and carers to explore their lives and coping mechanisms when things are difficult. They may also be involved in your family's care now and in the future.



Chaplaincy

Chaplains are here to help you explore questions regarding your life as it now is, your life as it has been, and as it is becoming. Spiritual care is not necessarily about a religion or faith.

When requested our chaplains can help you make plans for the future and to explore questions which arise for you regarding decision(s) you may wish to make. We can provide specialist support as requested in the community, the day hospice and the inpatient unit.

If you have a faith which is important to you but do not have an existing group to which you belong and would like to find one then every effort will be made to help you to establish the support you need. There are many questions which arise during a life changing event which often needs help to be explored and as part of the Hospice team chaplaincy can offer insight into some aspects of the questions which may arise for you.

If you have a faith to which you already belong and wish support from that community during your time in our care then always feel assured that we will help you to have this at all times.

Spiritual and pastoral care is available across the whole Hospice.

Bereavement team

In bereavement your family and loved ones will continue to be supported if they so wish.

Support is offered by trained volunteers, our chaplain or social workers as appropriate. One to one support is offered either at home or at the Hospice. There are bereavement support groups running throughout the year led by one of our team. Some people find them very helpful as they enable people in similar situations to come together. Family support can also be initiated during the patient's illness by referral to the Bereavement team who will appoint a specialist children's worker to support you and your child(ren).

The Department of Work and Pensions has a specialist department which offers help and support they can be contacted on the following numbers

Phone **0845 606 0265**

Phone **0845 606 0275** (Welsh)

Textphone **0845 606 0285**

Textphone **0845 606 0295** (Welsh)

Social work

Our experienced social workers work alongside our medical, nursing and other services to ensure that you and your family are well supported.

They:

- Offer listening ears and someone to talk to;
- Work with social services to provide care at home;
- Provide advice about your statutory rights and benefits (in association with the Citizens Advice Bureau);
- Can also work with you and your family to ensure that support is appropriate for all age groups both now and in the future.

Some medical conditions mean that you might be eligible for extra benefits and, in some cases, compensation. In these situations St Peter's Hospice will suggest you contact a solicitor or introduce a benefits advisor. Please feel able to ask any professional about this.

Support services

Volunteers

St Peter's Hospice volunteers enable us to continue to provide our high standards of care and support for patients and their carers. Our volunteers work in almost every area of the Hospice. They all sign our confidentiality policy and work alongside us to make sure you are well looked after.

Reception and coffee shop

Our reception desk is open from 8am to 8pm and is supported by staff and volunteers.

They will help you to feel "at home" at St Peter's Hospice, introduce you to the right staff members, direct you to the right rooms and help you over the telephone.

Our new, bright and modern reception area also benefits from a coffee shop (open from 10.30am to 6.30pm), giving our patients and their families a chance to buy a drink or something to eat.



Data protection: Under the Data Protection Act (2008) we need to make you aware that as a patient we keep electronic and, sometimes, paper records in relation to your care. These can be made available for you (for a small administration fee) and will only ever be shared by us with your permission and if another professional needs pertinent information.

Comments and complaints

Your feedback

As an organisation our aim is to provide the best possible services to anyone who has contact with us. This may be within the Hospice, in the community, in our shops or at fundraising events.

We are committed to providing a quality service to all our patients, carers and visitors. To do this we need to constantly look for ways of improving the way we work. You are in the best position to judge how we are doing and we certainly need you to tell us when we get it wrong.

We strive not to give cause for complaint but every one is recorded and acted upon. Quite often we can resolve a complaint immediately. If not, we will investigate your complaint fully and deal with it quickly and confidentially.

You can make a complaint, comment or suggestion or compliment an area of our work by completing a patient



satisfaction survey and returning it to the address on the form, writing a letter and passing it to a member of staff, leaving it at reception or posting to the address right:

**The Director of Patient Care
St Peter's Hospice
Charlton Road
Brentry
Bristol
BS10 6NL**

Alternatively you contact us as follows:

Tel: **0117 9159 400**
Fax: **0117 9159 473**

Web: **www.stpetershospice.org**

What happens to your comments?

Both positive and negative comments will be taken seriously.

It is extremely important that we recognise the need to continuously develop our services. Comments and suggestions from anyone can help us look objectively at what we offer. These comments and suggestions can be related to the hospice environment, the care, the food, the gardens, the way staff and volunteers work, the management, the parking and so on. It would be helpful if you could consider when making your comments what you might suggest as a solution, if you are able. When we receive a comment the Director of Patient Care will acknowledge this within five working days and will write to you again within twenty working days with a response to your comment.

What happens if I have a complaint?

Most difficulties can be resolved by speaking or writing to the manager of the department involved. Please ask a member of staff for their name. If you would prefer, you may wish to speak with, or write to, the Director of Patient Care or Chief Executive. When we receive your letter, we

will confirm that we have received and recorded your communication within two working days.

A senior manager will investigate your complaint and the Director of Patient Care will aim to send a full response outlining the findings within twenty working days of the receipt of your communication, unless there are complexities that make this impossible. In these circumstances we will write to let you know of the delay, and when we can expect to complete the investigation.

We will let you know the outcome of our investigation.

If you wish you can contact the Care Quality Commission for advice or help.

**South West Region
Care Quality Commission
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA**

Tel: 03000 616161

Email: enquiries.southwest@cqc.org.uk

St Peter's Hospice is required to provide evidence each year to demonstrate compliance with healthcare standards and is inspected at least every 5 years.

Contacting St Peter's Hospice

If you need advice or to contact your Clinical Nurse Specialist please phone **0117 915 9400** and ask to speak to the clinical administration team during office hours. Out of hours and over the weekend please ask to speak to the Inpatient Unit or use the advise line number: **0117 915 9405**.

St Peter's Hospice main switchboard: **0117 915 9400**

St Peter's Hospice Fundraising Office: **0117 915 9300**

St Peter's Hospice Shops Collection Services: **0800 583 0015**

www.stpetershospice.org

www.facebook.com/stpetershospice

Fundraising

Who we are

St Peter's Hospice is Bristol's only adult hospice caring for local people with life-limiting illnesses. Our commitment is to improve the quality of life of patients while extending care and support to their families and loved ones.

Mission and vision

Our Mission is to work in collaboration with healthcare partners to develop, influence and provide flexible specialist services that meet the needs of people with life-limiting illness.

Our Vision is that all adults in our local community living with life-limiting illness will have access to the best possible palliative care that is appropriate to their needs.

Who we care for

Last year we cared for over 2,200 patients and supported over 6,000 family members, including children. 85% of this care was provided in patient's homes.

How we are funded

All of our care is provided free of charge. It costs over £6.5 million and the NHS contributes just 25% of our annual running costs. For the rest we are totally reliant on the generosity of the public who support us through any number of different ways including:

- Fundraising events;
- The Local Lotto;
- In our shops;
- At work;
- In memory;
- Gifts in wills;
- Donations.

Find out more about St Peter's Hospice

If you would like more information about the work of St Peter's Hospice or any of our fundraising activities please complete the following form and return it to:

St Peter's Hospice Fundraising Office, 58 Royal York Crescent, Clifton, Bristol BS8 4JP

- I would like to receive the Hospice Newsletter.
- I am interested in finding out more about the ways in which I can support the work of the Hospice.
- I would like to share my story to help promote the work of the Hospice.

Title	Forename	Surname
Home address		
		Postcode
Telephone number		
Email address		

St Peter's Hospice will not pass your details on to anyone else. However we would like to keep in touch with news and information about our work. If you **DO NOT** wish us to contact you by the following means, please tick the relevant box:

- Phone
- Mail

If you **DO** wish us to contact you by **email** to tell you about our work, please tick this box:

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