



BIRMINGHAM
ST MARY'S
HOSPICE

**Patient
information
booklet**

Welcome

This booklet is to introduce you to Birmingham St Mary's Hospice and describe the ways in which we can work with you to help you and your family.

There is space at the back of this book for you to write down of some of the people involved in your care, your questions and important notes.

Birmingham St Mary's Hospice,
176 Raddlebarn Road,
Selly Park,
Birmingham,
B29 7DA

Telephone: 0121 472 1191

www.birminghamhospice.org.uk

Hello

We are Birmingham St Mary's Hospice and we provide free care and support to people and families across Birmingham and Sandwell who are living with life-limiting illness.

Our aim is to enable the best quality of life possible for you and your carers.

What the Hospice offers you

We will listen to what matters to you and:

- Understand your goals and hopes, to help you achieve them.
- Understand what makes you suffer; offer you treatment, support you to adjust and cope.
- Help you think and plan ahead, taking into full account your hopes, fears and priorities.
- Pay attention to the needs of your family and others you love, now and in bereavement.
- Provide practical support and 24 hour advice if you are in crisis.
- Coordinate our work with nurses, doctors and other health professionals important to you.

Depending on your needs, we will work with you in your own home, a local GP surgery or at our building in Selly Park, which has specialist Inpatient, Day Hospice and Outpatient facilities.

The rest of this booklet gives further information about our services and other useful information. Please do not hesitate to ask a member of staff to find out more about how we can work with you. We look forward to getting to know you.

Working together for you

We are a team of compassionate staff and volunteers with expertise in palliative and end-of-life care including: nurses, doctors, physiotherapists, occupational therapists, social workers, counsellors, spiritual carers, bereavement workers and much more.

We consider you and your family part of the team: you are the expert in yourself.

Volunteers are a vital resource and contribute enormously to the services we offer to our patients and their families. More than 400 volunteers dedicate their time and energy to supporting the Hospice helping in many areas, from bereavement counselling and complementary therapy to fundraising events and our Board of Trustees.

Services for you

Our staff and volunteers work in teams, each with particular expertise in an area of care. In this section there is a brief outline of how the following teams can work with you:

Specialist Community Palliative Care team of specialist nurses visiting you at home or meeting with you at a local GP clinic.

Hospice at Home team providing hands-on care during the last days and weeks of life in your own home.

Day Hospice offering a 12-week therapeutic programme and the Welcome Group.

Inpatient Unit offering admission for intensive symptom control, support in crisis and care for the last days of life.

Therapies team offering you physiotherapy, occupational therapy and complementary therapy.

Family and carer support team focusing on your social, emotional and spiritual needs including bereavement support.

The teams **all work together** to support you.

Specialist Community Palliative Care Team

Our Community Palliative Care Team is made up of clinical nurse specialists (CNS) with extensive experience and knowledge of palliative care. Your CNS can see you at home, as an outpatient at the Hospice or in clinics across Birmingham to suit you.

Your GP will continue to have overall responsibility for your medical care and your District Nursing team will continue to have responsibility for the nursing care they provide. Your district nurse will be your key worker (the person with responsibility for coordination of your care) for your palliative care needs. If you are not known to the District Nursing team, with your permission, we will ensure a referral for their input with your care is made.

The CNS' expertise in palliative care means they can work with, support and advise your GP and district nurse to ensure effective symptom relief. The CNS could arrange for one of the Hospice medical staff to visit you or for you to attend an outpatient appointment. He or she could also arrange a stay in the Inpatient Unit to provide symptom relief for you.

Your CNS is also the person who can arrange for you to take advantage of other Hospice services, such as the Day Hospice.

The Community Palliative Care Team is available from Monday to Friday from 9.00am until 5.00pm. Additionally, there is one member of the Team on duty on Saturdays, Sundays and Bank Holidays from 9.00am until 5.00pm.

Outside these hours, a CNS is on-call for specialist palliative care advice which cannot wait until normal working hours. This is not an emergency service and does not replace the service provided by your GP (or out-of-hours provider) or your District Nursing Team.

Sometimes the reasons patients are referred to the Community Palliative Care Team get resolved. For example, symptoms may no longer be a problem or there may be an overall improvement with the medical condition. In such situations, patients will be discharged from the Community Palliative Care Team. Patients can, of course, be re-referred should they require the specialist care provided by the team again.

Home Visits

When your CNS, or any other worker from the Hospice, calls to see you in your home, we would kindly ask you to please not smoke during the visit.

Hospice at Home

Hospice at Home is for people who are at the end stage of their illness and prefer to be cared for and die at home. Care is provided in the home in partnership with you, your family, your district nurses and alongside the GP.

Hospice at Home provides personal care, nursing care, support, advice and emotional care by a team of registered nurses and nursing assistants.

Care is provided for approximately two weeks. Care is delivered seven days a week between 8.30am - 6pm.

Day Hospice

Our Day Hospice facility is in our building at Selly Park, which overlooks the park. We offer a 12-week therapeutic programme or the Welcome Group according to what your needs are.

Therapeutic course

Day Hospice can support you with physical, emotional, spiritual or social concerns that come with life-limiting illness, through a 12-week structured programme.

The Day Hospice is open from 10am until 3pm on Tuesdays and Thursdays. We welcome 15-20 patients once a week for 12 consecutive weeks.

Whilst attending Day Hospice you will have the chance to understand symptom management individually and in group discussions, and time to discuss your future wishes and priorities. Physiotherapists, occupational therapists and complementary therapists are available to help you live well with your illness and achieve your goals. There will be therapeutic activities on offer every session, such as relaxation, gentle exercise, arts/crafts, gardening and other leisure activities. You will be offered snacks and drinks throughout the day and a cooked lunch.

If you are not able to make your own way, we may be able to offer transport to and from the Day Hospice, thanks to our team of volunteer drivers. They use either a Hospice vehicle adapted to take wheelchairs and oxygen, or their own cars, according to your needs.

Many people attending Day Hospice say that the greatest benefit of all is the opportunity to meet and talk to other people in similar situations as far as their health is concerned. In addition to the support from peers, the multi-professional team at Day Hospice includes physiotherapists, occupational therapists, nurses, spiritual care workers, complementary therapists, doctors and more.

Welcome group

Welcome group is a volunteer-led support group for you, which offers peer support and time with people living with similar health circumstances. The group meets in the Day Hospice every Wednesday from 10am-3pm. You need to be able to make your own way to the Hospice. Drinks, snacks, a hot meal and good company will be provided.

Smoking

Smoking is not permitted in the Hospice premises or grounds, however patients can access the adjacent park. Patients who choose to smoke are asked to sign a disclaimer regarding smoking off-site. Smoking is not permitted in the Hospice vehicles.

Inpatient Unit

The Inpatient Unit is in our building in Selly Park overlooking the park. It is available when you need: intensive symptom management, support with emotional or social crisis, or care for the last days of life. We do not offer long-term care and the average stay for most patients is two weeks.

Many patients return home, some choose ongoing care in a nursing or residential home and others spend their last days being cared for on the Inpatient Unit.

It is made up of single rooms and small wards with a communal garden, conservatory, lounge area and Peace Room. There is also the 'Harry Moseley Family Centre', which is a small, private centre with a kitchen, two bedrooms and a living room for patients who have a family member or friend who would like to stay with them at all times.

The team of nurses, doctors, therapists and others will have time to spend with you and your family, talking, listening and helping you with what matters most to you. Our team have expertise in managing symptoms like pain, breathlessness and others.

Our staffing levels are much higher than in hospital so that we can help you be understood, safe and comfortable.

You will also have the opportunity to talk to a member of the Family and Carer Support Team about financial concerns, emotional support, preparing for bereavement, spiritual support, help with grants or benefits and much more.

Smoking

There is a designated Smoking Shelter in the Hospice garden (for patient use only). No other smoking is permitted on the Hospice premises.

Family and Friends

Your family and friends may visit you at any time; though we do ask you to bear in mind that there are some times in the day where your visit is more likely to be interrupted because of care activities. This could be during mealtimes, medicine rounds, bath times and times when cleaning is taking place. If you are in one of the small multi-bedded wards, we would ask you to respect the privacy and needs of other patients.

Your pet may visit at the discretion of the nurse in charge. Please discuss this with them.

Your medication

Please bring in all medicines that you have been taking so that we can prescribe and supply the correct medicines for you. We will recommend how medicines can help with your symptoms and monitor you closely to ensure your treatment is just right for you. Our high standards of up to date evidence based care include using medicines beyond their licence. If you would like to understand more about 'using medicines outside of their licence', we have a leaflet available which explains all aspects of this, or you can ask your doctor or nurse for more information.

Our supply of medicines and pharmacy advice are provided by the Pharmacy team from University Hospital Birmingham Foundation Trust Pharmacy. A dedicated pharmacist and technician spends time at the Hospice dealing with supplies of medication, information and monitoring to ensure that you get the maximum benefit from prescribed medication.

Upon discharge, we will provide you with one week's worth of medicines for use at home, as well as information for your GP about your medicines so that he/she can continue them at home for you.

Planning and Discussing Your Future Care

There will be opportunities to talk about what living with a serious illness means to you, your family or carers. You may like to plan ahead, particularly if you anticipate becoming unable to make decisions for yourself. You will have the opportunity to think and talk through what your preferences and wishes for future care and treatment might be. Doing so may address some of your fears and help you feel more in control. This is, like all aspects of your care, optional and on your terms.

Resuscitation

Cardio-pulmonary resuscitation (CPR) is an emergency medical treatment aimed at restarting the heart and breathing in a patient who has suddenly and unexpectedly collapsed – usually as a result of a heart attack or heart irregularity. For many patients who come to the Hospice, CPR is not appropriate because death is not due to sudden unexpected heart irregularity, but rather the consequence of advanced incurable disease. Unfortunately CPR does not restart the heart or breathing in this situation so it is not attempted. Instead we focus on best quality of life right up to end of life and, when death comes, ensuring it is as peaceful and dignified as possible.

If you would like more written information about this, there is an information leaflet available. You will be able to discuss resuscitation with staff during your stay, along with any other aspect of treatment planning for your future. You do not have to discuss it if you would prefer not to.

When will I be offered a bed?

We assess those waiting for a bed on the Inpatient Unit every day, so that we offer admission to those in most urgent need as soon as possible – the same or next day if possible. Sometimes there is a wait of several days during which time we will stay in touch and support you at home. We can usually let you know the day before that a bed is going to be available. When your needs are urgent or our bed situation changes, we also offer admission on the same day. If you want an update whilst waiting for admission, please contact our triage nurse on **07726 580153**.

What to bring?

Please bring all medication that you are taking at the time.

You will also need to bring your night clothes, slippers and usual toiletries, as well as day clothes you may want to wear. You will have a locker for your belongings, but please be aware the space is limited. We ask that you make arrangements with family or friends to do your laundry. Please let a member of staff know if this is problematic for you.

We ask you not to bring valuables or large amounts of money. We have a system of logging any items you bring with you and a small amount of space in a safe in our Finance Department if you have to bring cash in. If you want to keep cash or valuables with you, we will ask you to sign a disclaimer.

You are welcome to bring in personal electrical equipment – for example, a hairdryer or shaver. We request that you allow our maintenance staff to carry out quick PAT (Portable Appliance Test) as part of our fire safety procedures. Please mention to a member of staff any electrical equipment you have with you.

Individual televisions, some with DVD players and fans are available for all patients.

What are visiting arrangements?

Your visitors are welcome any time. We ask that they are considerate to the needs of other patients especially if you are in a shared area. We have limited overnight accommodation for visitors wishing to stay that is allocated on a day-by-day basis according to need. If you are too tired for visitors, then we can agree with you specific visiting and rest times to suit you and your family and friends. Your visitors will be asked to sign in and wash their hands. You are welcome to use some of the shared spaces (for example, the garden and conservatory) to share time with your visitors.

What about food?

Our nursing staff will talk to you about your dietary needs and preferences and work with the catering team to offer you food and drinks you can enjoy free of charge. Information about mealtimes, menus and snacks will be shown to you when you arrive.

For your visitors, we have a daily menu they can choose from for a small charge. Alternatively, there is a microwave and vending machine for drinks and snacks. On Raddlebarn Road there are several convenience stores and take-aways.

And drink?

In the spirit of enjoying the best quality of life, you may like to drink alcohol. We understand that it can be part of celebrating special times with family and friends and can add to the enjoyment of meals. We recommend you discuss with your doctor or nurse safe alcohol use alongside your medicines. While we will allow people to drink alcohol, we will ask intoxicated visitors to leave.

How can I stay in touch with home?

As mentioned, your visitors are welcome any time, but you may also bring in and use your own mobile phone. We do ask you to be considerate to the needs of other patients and visitors. There is Wi-Fi access for patients and visitors. Please ask a member of staff for the password. We also have a laptop computer available to borrow.

Please ask friends and relatives to address letters and cards with your first and last names and to mark as Private and Confidential to prevent it being opened. The postal address of the Hospice is:

**Birmingham St Mary's Hospice,
176 Raddlebarn Road,
Selly Park,
Birmingham,
B29 7DA**

Physiotherapy, Occupational Therapy and Complementary Therapy

Our team of therapists will work with you to identify and achieve your personal goals; whether they be managing a symptom (such as pain, breathlessness, tiredness, swelling or anxiety), finding new ways to bathe, moving safely or enjoying meaningful activities. To help you achieve your goals we will offer you symptom control techniques, rehabilitation, equipment, exercises, massage, relaxation techniques, aromatherapy and acupuncture.

Our physiotherapists and complementary therapists will work with you on the Inpatient Unit and in Day Hospice. Our occupational therapists can also visit you at home, for example, to assess and provide useful equipment for your independence, comfort and safety.

Our therapists will work closely with everyone else caring for you, including your family, carers, the rest of the hospice team and the therapists based in hospitals or in your community.

Family and Carer Support Team

We care about your family, carers and loved ones and aim to understand and meet their needs too. Please help us by telling us who is important to you, who you worry about and who you share information about your health and care with. We have a team of social worker, spiritual carers, counsellors and volunteers whose focus is on emotional, spiritual and social issues that you, your family and carers are facing.

Emotional and practical help

We can talk to you about your illness and how it affects your life. We can also support you with practical matters. For instance, you may have particular wishes that you want to carry out or want help in writing a will or letters to loved ones. We can also help you to deal with a wide variety of concerns, for example, funeral planning, financial worries, housing issues, grant applications and finding information and assistance.

Spiritual Care

We promise to see you as a person and not “just” as a patient with an illness or a carer for a patient. Your hopes, fears, sources of joy and suffering are relevant and important. We appreciate that living with a life-limiting illness can cause you to look afresh at meaning and purpose of your life. Physical health problems can take attention away from caring for your spirit and leave you not feeling like yourself. We will help you find the space, time and courage to think and talk about what matters to you. Through listening, caring, understanding and connecting we will help you be yourself.

The staff and volunteers in our Spiritual Care team have a special interest and expertise in your spiritual wellbeing. The team comes from diverse religious and spiritual backgrounds and are able to offer pastoral, religious and spiritual support to patients and their families of all faiths and no faith.

Our Peace Room is fully equipped to cater to the spiritual needs of all. We encourage friends and relatives to make use of this room to pray, remember, appreciate or simply to spend time in the tranquil space.

Support at Home

Support at Home provides trained volunteers to visit you at home and offer friendly companionship and a listening ear.

Your family, carers and loved ones may feel that they would like the chance to have a break for a few hours, but don't want to leave you on your own. Our volunteers can support the people who matter most to you by allowing them to have a few hours to relax, visit friends or run errands, knowing that you have someone with you to keep you company and make sure that you can manage while they are not there.

Bereavement Support

We understand that bereavement can be isolating and can provoke strong feelings that can be difficult to talk about and manage. We offer you a safe and confidential space to talk about your feelings with one of our trained bereavement workers or counsellors. We can also offer you help with the practical problems that can arise after someone has died and the difficulties with day-to-day living. You can be supported at the Hospice or at home and this help can be given at any point after your loved one has died.

You are welcome to join the A Time to Remember ceremony, held regularly in memory of loved ones.

If your partner has died, you are welcome to join The Chrysalis group, our fortnightly support group.

We can provide you with more written information in our Your Life After Loss leaflets: *A Practical Guide to Coping with Grief*. Please ask a member of staff for it or you can find it on the Hospice's website.

Child Bereavement

We offer you expert support for the children in your family and those caring for them. Our dedicated children's workers work with children at home, in our children's 'Roots and Wings' room, in groups and/or alongside schools. We can support children with their needs using play, talking and creative activities to help them express feelings, ask questions and find ways of coping, making and recording memories.

We can also support you as a parent or carer with your emotions and questions about how best to support a child.

We tailor the support for your child and family depending upon their age, personality and interests. Support is available at the right time for the child - this might be when someone they love is first faced with life-limiting illness, when someone they love is dying or has recently died or alternatively long after bereavement.

Our booklet *'The ground feels wobbly'* offers more detail about supporting children and young families before and after someone dies.

Other Useful Information

Education and Research

We are a teaching hospice providing education to other healthcare professionals about compassionate high quality palliative care. As part of this we have professionals training with us including nursing and medical students. You will always be asked permission for them to be involved with your care.

We are involved in research with a range of studies at any one time, answering questions about which treatments are best and what patients prefer. You may be approached to see if you'd like to participate, which is entirely optional. Our research is designed to advance our understanding of best practice in palliative care and we share our knowledge through teaching, training and doing.

Valuing Diversity

We are committed to providing high quality services that are open, culturally aware and equally available to all. Our services are available free of charge for you whatever your diagnosis, faith, preferred language, living circumstances, sexual orientation, health or other beliefs. We use interpretation and signing services because communication and understanding is essential. We work with people at home, in care homes, when they are homeless, in prisons, at a family member's home and much more.

Your Information

The Hospice keeps records about your health and treatment. This helps to make sure that you receive the best possible care, by ensuring that everyone involved in your care has up-to-date information.

This information forms part of your Hospice record and is kept in a computer system and paper notes. The information we record includes:

- Basic details about you as an individual (name, address, date of birth, NHS number, etc).

- Information about the care you receive from the Hospice and any treatment you receive including test results.
- Information relevant to your care from other individuals including your GP, hospital consultant, carers, family and next of kin, and any information you have given us.

We will ask you whether you'd like us to share information with others providing you with care outside of the Hospice, such as your GP, hospital doctors and nurses.

We will also ask you what aspects of your treatment and care you are happy for us to discuss with your family and carers, and which you would like to be kept confidential.

How we handle your information

We have a legal responsibility to keep your information confidential in accordance with the NHS Confidentiality code of Practice and the Data Protection Act 1998. We have security policies to protect your information. All staff and volunteers have training on confidentiality and are required to sign a confidentiality agreement.

We will ask your consent to use your information for any purpose other than providing your care. For example, we may approach you to ask if your information could be used to help with teaching, or research, or fundraising. This is entirely optional.

Some information is used for statistical purposes. We take strict measures to ensure that you cannot be identified when information is used for this purpose.

Can I see my information?

Under the Data Protection Act and the Access to Health Records Act, you can ask to see information in your record.

I have more questions

If you have any questions about how we use your information, please ask to speak to our Data Protection Officer.

Gifts

Hospice staff are flattered and encouraged by the generous gratitude of patients and families. However, staff are not allowed to accept personal gifts from patients, relatives or other visitors.

Compliments, Complaints and Suggestions

We welcome your feedback as your views help us to uphold and improve the quality of our care. Please speak to us at any time about this or use compliments, complaints and suggestions boxes on the Inpatient Unit and in day Hospice. We will also give you a short questionnaire inviting your feedback.

If you do have any concerns or want to make a complaint, please speak to a nurse, doctor or other staff member with whom you are involved in the first instance. Alternatively, you can speak to the director of nursing or the head of human resources.

The Hospice, along with all health care providers, has to by law have a complaints policy and process. If you want information about this, or would like a copy of the leaflet 'Compliments, Complaints and Suggestions', please ask any member of staff.

If Hospice staff are not able to deal with your complaint to your satisfaction, you have a right to contact the Hospice's regulatory body, the Care Quality Commission (CQC).

The contact details are:

CQC National Correspondence, Citygate, Gallowgate,
Newcastle upon Tyne, NE1 4PA

Tel: 03000 616161 Fax: 03000 616171 Email: enquiries@cqc.org.uk

The CQC website (www.cqc.org.uk) also has provision for you to add comments about your experience of our service at:
<http://www.cqc.org.uk/directory/1-135262858>

Where are we?

The Hospice is situated on the corner of Warwards Lane and Raddlebarn Road immediately adjacent to Selly Park Recreation Ground.

The post code for satellite Navigation devices, is: **B29 7DA**

By car from the city centre - Take the A38 (also known as the Bristol Road) out of the city centre signposted for Bromsgrove, Selly Oak and Redditch.

By rail - A local train service runs from Birmingham New Street Station to Selly Oak Station every 15 minutes. It takes 10 – 15 minutes to walk from the station to the Hospice. For national rail travel information, please use the website www.nationalrail.co.uk

By bus - Bus number 76 stops immediately outside the Hospice and operates between Solihull Town Centre via Shirley, Yardley Wood, Kings Heath, Selly Oak and terminates at University Station, by the University of Birmingham.

Bus numbers 61, 62 and 63 travel from the City Centre along the A38 Bristol Road to Dawlish Road. You can then walk up Dawlish Road until you get to Raddlebarn Road. Turn left and Birmingham St Mary's Hospice is on the right hand side of the road. It takes about 10 minutes to walk. Bus number 45 and 47 travel along the Pershore Road A441 and you will need to walk through Selly Park to get to the Hospice using Upland Road or Kensington Road.

For more information on bus/train timetables in the West Midlands, please call the Centro Hotline on 0121 200 2700 available from 7.30am-10.30pm or call 0870 608 2608.

Alternatively visit www.centro.org.uk or www.travelwm.co.uk

Access and Car Parking Information

Our car park is available to use free of charge. Access to our rear car park is gained from Raddlebarn Road. The entrance is opposite Teignmouth Road. If our rear car park is full, there is also a council car park adjacent to the Hospice car park. Again, no charge is made for parking. If both car parks are full, there are spaces on Raddlebarn Road directly outside the Hospice (parking restrictions apply), or in the surrounding side streets.

For safety and security reasons, we ask visitors to the Hospice to sign in and record car registration numbers at Reception. Please park in designated parking spaces only. Please ensure that spaces marked for Disabled Blue Badge Holders are used correctly. Care should be taken not to block entrances and exits to any part of the grounds or the access road because access is needed for deliveries and emergency vehicles.

If your car is to be parked on site continuously for more than a couple of days, please let reception staff know about it. The Hospice is not able to accept responsibility for vehicles and their contents parked on site, or in the surrounding area.

How you can help us?

We look forward to working with you and your loved ones, but there are lots of ways that you can help us continue to provide good care for yourself and others.

- **Please give us helpful feedback- tell us what we are doing well and where we can improve**
- **Share your story - to inspire, reassure and teach others**
- **Participate in research to improve care for future generations**
- **Make a donation**
- **Give in memory of someone who has died**
- **Pledge a donation in your will**
- **Take part in a fundraising event**
- **Volunteer – see our website for volunteering opportunities**

For more information, please speak to a member of the team or see our website.

Find out more

Speak to us and ask anything.

Please speak to a member of our team if you have any questions or queries. You can also look at the Hospice website where you can find lots of information about our work and how patients, their families and professionals can access help.

www.birminghamhospice.org.uk

To keep up-to-date with news about the Hospice, please like us on Facebook:

facebook.com/birminghamstmaryshospice

or follow us on Twitter: **[@brumhospice](https://twitter.com/brumhospice)**

Your notes

You may want to write down your key contacts here:

My District Nurse is:

Name:

Telephone Number:

My GP is:

Name:

Daytime Telephone Number:

Out of hours Telephone Number:

My Clinical Nurse Specialist is:

Name:

Telephone Number:



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