

# Information for patients and their families



St Barnabas House provides palliative care for adults with advanced life-limiting illnesses. Palliative care cannot cure a disease but is the active total care of patients, their families and carers. It aims to relieve symptoms that are often associated with illnesses and their treatments – for example nausea, pain, anxiety. The aim is to achieve the best possible quality of life for you, your family, friends and carers. St Barnabas House strives to ensure you have access to hospice services at the right time in your illness. Hospices aim to provide care and support to the ‘whole person’, not just the symptoms that are experienced and therefore a whole range of services are available to support your needs.

A copy of our Statement of Purpose can be viewed in the hospice, on our website or is available on request from the Director of Adult Nursing at St Barnabas House.

*“I just pray that for myself and everyone you look after that you can continue both your in-patient and outreach facilities – I am sure to myself and many others the difference it makes to our lives is immeasurable.”*

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## The organisation and funding

As an independent charitable organisation, St Barnabas House receives some funding from the local NHS Commissioners. We are, however, reliant on the generosity of individuals and the community for the majority of our funding needs each year. We care for people in the area from Littlehampton in the west to Southwick in the east and north to Steyning, Henfield and Storrington.

The hospice makes no charge to patients or families for care provided.

## In-patient Unit

The In-patient Unit has 20 single rooms, five of which are family rooms which include space for relatives who wish to stay.

The nursing team consists of a mixture of trained nurses and experienced nursing assistants. They work closely with the rest of the hospice team to provide excellent care. On admission you will be allocated a pair of key workers who will take the lead in co-ordinating your care. One of these nurses will sit down with you soon after your admission and discuss with you what you hope to get out of your stay. The hospice team aims to offer a friendly, relaxing and calm environment. We encourage you to dress as you would at home. You can also make use of the hospice gardens and go out of the hospice for visits if you wish during your stay.

## Length of stay

Length of stay in the hospice is based on your individual need and your reason for admission. Staff will discuss this with you.

The three main reasons for admission are:

**Symptom Control:** Aimed at relieving persistent, difficult symptoms, such as pain or nausea, that are not resolving within your home or the hospital environment. This will be done through comprehensive medical and nursing assessment, incorporating physiotherapy and occupational therapy, psychological and spiritual support if required, together with a review of your medication and care. This would usually last between one and two weeks.

**Respite Care:** For one to two weeks, decided in advance of your stay, enabling your usual carer to take a break. If your condition is stable, your care will usually be supervised by the nursing team. This means you would not routinely see a doctor during your stay.

**End of Life Care:** If your choice is to die in the hospice, we will try to facilitate this where possible. The In-patient Unit is not able to offer long-term care, although some people will have several admissions over a period of time. Should you be unable


to go home following admission and need long term supportive care, the hospice team will work with you and your family to find an appropriate alternative residence.

## Visiting

Family, including children, friends and professionals, are welcome to visit you on the In-patient Unit and we will support your wishes regarding visiting.

Pets are generally welcome but please check with a nurse beforehand. We would recommend that visiting before 2pm is avoided where possible in order to ensure fewer interruptions to your care. If you have any specific requests about visiting, please let one of the nurses know.

We would ask that visitors who have experienced vomiting, diarrhoea or flu symptoms within the previous 48 hours do not visit.



*“Our whole concept of the hospice changed for the better.”*

## The scope of treatment available at St Barnabas House

The doctors and nurses at St Barnabas House have the skills needed to control difficult symptoms in patients with life-limiting illness. Our goal is to achieve comfort and maintain your quality of life within the limits of what is realistically achievable.

The medical care is therefore quite different from that available in hospital, in that we do not undertake intensive technical procedures that require complicated monitoring. However, if you develop a serious but treatable problem and would benefit from intensive medical treatment, we will discuss this with you. If necessary, we will arrange for you to be admitted to hospital.

The hospice has limited resuscitation facilities to cope with a sudden unexpected collapse such as a cardiac arrest. (Resuscitation involves thumping your chest, or delivering electric shocks to restart your heart and breathing.) The majority of patients under our care are approaching the end of life and

would not survive this procedure. We therefore do not offer it as a matter of routine as it would only result in an undignified death. We will discuss our policy with you and any concerns you may have.

Hospice staff will readily discuss your treatment and care with you, giving you opportunities to express your wishes and address your concerns. We appreciate that this is a difficult time for you and your family and that you may find some things difficult to talk about. We aim to be sensitive and supportive in our conversations with you.

Some patients find it helpful to express their wishes in the form of a 'Living Will', otherwise known as an Advanced Directive. These help us to respect your wishes should you no longer be able to make decisions for yourself. It is often also helpful to share your wishes with those closest to you, as we will usually ask them to represent your views if you are unable to tell us yourself.

*"This has all had a positive effect as to how I feel about myself."*

# Day Hospice

The Day Hospice is open from Tuesday to Friday, offering a clinic on a Monday for new referrals. The Day Hospice is a nurse-led unit, supported by a large team of volunteers. If a relative or friend is unable to transport you to the Day Hospice, we may provide you with volunteer transport, depending on your mobility.

The Day Hospice aims to provide a place for wellbeing, relaxation and friendship in a supportive and helpful environment. The Day Hospice Team is able to offer advice on the

management of complex symptoms, spiritual, emotional and social issues. Physiotherapy, occupational therapy and complementary therapies, such as reflexology and massage, are available. Activities include entertainment, visits, projects, workshops and the opportunity to spend creative time in our art room.





## St Barnabas Community Team

The Community Team provides specialist palliative care and advice to people at home, in nursing and residential homes and community hospitals.

The team consists of Registered Nurses, nurse specialists, and doctors. This includes nurses specialising in the care and support of patients with advanced respiratory, renal, heart, and liver disease.

Each nurse provides expert knowledge in symptom control together with emotional support to you and your carers. They work alongside your GP and district nurse who remain responsible for your medical and nursing care at home.

## Hospice at Home Team

St Barnabas House Hospice at Home Team can help to support people requiring palliative care to stay in their own home, if this is their preferred place of care. It is an additional service to those already offered by St Barnabas House.

Our Hospice at Home Team consists of trained nurses and healthcare assistants. We work alongside your own GP and community nurses. We will work together to ensure your care is co-ordinated and right for you.

We will only provide short term care. This may mean visits several times a day. The length of time and frequency of our visits will depend on your needs.



## Family Services Team

Through its counsellors, social workers, chaplain, support staff, and experienced volunteers our Family Services Team offers psychological and spiritual support, as well as advice and information to you, family members, and friends. This can be provided to individuals, couples, or family groups, in the hospice or at home, and might take the form of one-off, occasional, or regular support according to your needs.

There is a chapel service on a Friday afternoon to which all are welcome.

The Bereavement Team offers individual and family support to adults and children as well as opportunities to meet with others who have also been bereaved.

## Complementary Therapies

A team of qualified complementary therapists are able to offer a number of therapies including massage, aromatherapy, reflexology and relaxation to patients in the In-patient Unit or in the Day Hospice.

The treatments they offer are free. They aim to be soothing, relaxing and comforting and can be carried out whilst you are in your bed or reclining in a chair. They can be used alongside other treatments that the doctors and nurses are using to help with symptom control. The therapies available are all gentle and adapted to suit your individual needs once you have been assessed.

*"She always was a lucky lady and even at the very end, when her luck seemed to run out, she had the fortune to end her days at St Barnabas House."*

# Therapy Team

The physiotherapists and occupational therapist work as part of the hospice team and will see patients in the In-patient Unit, in the Day Hospice and at home. Physiotherapy and occupational therapy aims to improve your quality of life and help you to remain as independent as possible through all the stages of your illness.

## Physiotherapy

Symptoms that physiotherapy may help include:

- Loss of independence
- Difficulty with walking
- Muscle weakness
- Breathlessness and other breathing problems
- Pain
- Swelling and stiffness
- Anxiety
- Fatigue

Following your physiotherapy assessment, realistic goals and a treatment plan will be agreed with you. Physiotherapy treatments are tailored to your needs and may include:

- Exercises to strengthen and/or improve joint mobility
- Advice on walking
- Breathing exercises and techniques
- TENs and acupuncture
- Advice on relaxation techniques
- Advice on conserving energy
- Advice to carers

## Occupational Therapy

Occupational therapists work with you to keep you as independent as possible by adapting your environment and/or looking at different ways of doing everyday activities.

Your occupational therapist will work with you towards agreed goals for a set amount of sessions.

Occupational Therapy can help you with:

- Loss of independence and role
- Functional activity such as cooking, washing, and dressing
- Relaxation techniques
- Fatigue and anxiety management
- Equipment provision
- Moving and handling advice
- Posture and seating assessments for wheelchairs and armchairs
- Lifestyle advice and adaptive techniques
- Advice for your carers

## Artist-in-residence

Everyone has a story to tell, from everyday incidents to life-changing moments. There may be memories or aspects of your life that you would like to capture on film, in a poem or book, through music or photographs. The hospice has linked with the Rosetta Life charity to employ an artist-in-residence who can help you tell your story.

The artist works alongside patients in the In-patient Unit, in the Day Hospice or in their own homes. Celebration events are held regularly to share the work people have produced with friends and family. There is also a website where work can be exhibited at [www.rosettalife.org](http://www.rosettalife.org).

*"I discovered talents I didn't know I had, and am now doing some artwork at home."*

*"I felt a real sense of achievement at seeing my work on display."*



## Data Protection

Following referral to the hospice, a nurse or doctor will carry out an initial assessment. The role of the hospice will be explained at this time and important information will be obtained from you so that the most appropriate services can be offered. Besides asking about relevant medical details, inquiries will be made about emotional, financial, and spiritual concerns. We will also ask about relevant family members in order to find out their needs.

The person carrying out the assessment will explain how this information is used to provide care, and that it may need to be shared with other health professionals to provide you with the best care. You will be asked for your consent for this to happen. All patient and client records held by the hospice will comply with the requirements of the General Data Protection Regulations 2018.



*"After the initial apprehension of new surroundings and new people to care for mum, I found everyone I dealt with to be highly professional, showing a genuine care for mum's welfare."*

## Support for family and friends

### Confidentiality

The hospice respects the need for privacy and maintains its legal and ethical obligations with respect to confidentiality. All patient and client information remains confidential to the hospice, even after a patient ceases to be under our care.

If visitors enquire as to whether someone has been admitted to the hospice, it is our usual policy to let them know. If you do not wish this information to be released, please inform a member of staff on admission. Hospice staff are happy to have discussions with relatives or carers about your care, providing you give your consent

When someone dear to you becomes ill, it can be a distressing, frightening and lonely time which may leave you with a sense of helplessness and loss of control. Family members may protect each other, by not talking about what is happening, which can increase the sense of isolation.

We believe that support for family and friends is as important as the care we offer the patient. We are therefore very willing to give you time to talk about what is happening from your perspective and offer you emotional support. You may also have questions about the person's illness or treatment that you want to ask. We are very happy to answer these, providing we have the patient's consent to discuss these matters with you.

## The Education Department

The Education Department is an important part of the hospice, which provides education for lots of different people who may be involved in your care. The education programme is based on promoting the best possible care for our patients and support for their family and friends. The programme is specifically designed each year following discussion with patients, carers and professionals. The goal is to provide teaching sessions that match the needs of those people receiving and those people giving the care.

We are always keen to hear your views and opinions and would welcome any suggestions you may have.

## Maintaining standards

St Barnabas House is required to maintain and develop standards set as a result of government legislation. These are monitored by the Care Quality Commission, which is an independent body that has a statutory duty to regulate the independent healthcare sector, including hospices.

We are registered with the Care Quality Commission which means that we are inspected in accordance with legislative guidance.

You are able to read the report of our annual inspection on their website [www.carequalitycommission.org.uk](http://www.carequalitycommission.org.uk).



## Complaints, concerns and feedback

If you are concerned about the care or service you or a relative are receiving, please talk to a member of staff involved as soon as possible and let them know. We will always aim to resolve problems as they arise.

If you are dissatisfied, or have any concerns, please tell a member of staff and they will do their best to resolve the matter there and then.

Please be assured that raising a concern or making a complaint will not affect your care either now or in the future. We promise to listen carefully, find out what went wrong and do everything we can to resolve the issue.

Your details will only be shared on a need to know basis although the subject of the complaint and outcomes may be shared for wider learning.

If you wish to make a formal complaint you can do so by contacting:

📍 Hugh Lawson, Chief Executive  
St Barnabas House, Titnore  
Lane, Worthing, West Sussex,  
BN12 6NZ

✉️ [h.lowson@stbh.org.uk](mailto:h.lowson@stbh.org.uk)

This inbox is monitored by the Chief Executive Officer, PA to CEO, Director of Adult Nursing and Clinical Director.

If you remain dissatisfied, you may request an independent review of your complaint by the Health Service Ombudsman, who can be contacted at:

🌐 [www.ombudsman.org.uk/  
make-a-complaint](http://www.ombudsman.org.uk/make-a-complaint)  
📞 0345 015 4033

Or you can contact the Care Quality Commission (CQC) who are responsible for regulating St Barnabas House

🌐 [www.cqc.org.uk/content/complain-  
about-service-or-provider](http://www.cqc.org.uk/content/complain-about-service-or-provider)  
📞 Telephone: 03000 616161  
✉️ [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)

*"The attention to support and care started at the main reception desk through all the departments via catering, auxiliary and staff, indeed everyone that you came into contact with."*

## Hospital Palliative Care Team

Western Sussex Hospitals NHS Trust, which includes Worthing Hospital, has a hospital-based Palliative Care Team, consisting of nurse specialists and a consultant. They give specialist advice and support to hospital in-patients, as well as to the doctors and nurses looking after them. St Barnabas has close links with the Hospital Palliative Care Team, but this service is completely independent of the hospice. So being



under the care of the hospital team does not mean that you are also automatically under the care of the hospice, although the hospital team may refer you for hospice care, with your permission.

If you are admitted to Worthing Hospital, we can liaise with the Hospital Palliative Care Team to provide them with relevant information.

## Useful external telephone numbers



### End of Life Care Hub (ECHO)

ECHO nurses give advice and support in relation to end of life care over the telephone, as well as liaise with other specialist nurses and doctors. ECHO are available to contact 24 hours a day, every day of the year.

 01903 254789  
 [www.echocws.org](http://www.echocws.org)



### Integrated Care 24 (IC24)

IC24 provide GP out-of-hours services in Sussex. You may be directed to their services by NHS 111 should the advice of a Primary Care Clinician be required outside of a GPs normal opening hours.

 111  
 [www.ic24.org.uk](http://www.ic24.org.uk)

### NHS 111 service

The NHS 111 service is a free helpline staffed 24 hours a day, 7 days a week, by a team of trained advisers who can assist with any urgent, but non-life threatening, medical concerns.

 111  
 [www.england.nhs.uk/urgent-emergency-care/nhs-111](http://www.england.nhs.uk/urgent-emergency-care/nhs-111)



🏠 St Barnabas House, Titnore Lane, Worthing, West Sussex  
BN12 6NZ

📞 01903 706300

📞 01903 706396

🌐 [www.stbh.org.uk](http://www.stbh.org.uk)

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