Specialist Palliative Care in the Community

Douglas Macmillan Hospice
Barlaston Road
Blurton
Stoke-on-Trent
ST3 3NZ

tel: 01782 344 300
fax: 01782 344 331

DMHospice.org.uk
Registered Charity Number: 1071613
Company Number: 03615904
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Douglas Macmillan Hospice Community Team</td>
<td>2</td>
</tr>
<tr>
<td>24 Hour Advice Line</td>
<td>3</td>
</tr>
<tr>
<td>Reasons why you have been referred</td>
<td>3</td>
</tr>
<tr>
<td>What to expect</td>
<td>4-5</td>
</tr>
<tr>
<td>Planning for your future care</td>
<td>6</td>
</tr>
<tr>
<td>What matters to you</td>
<td>7</td>
</tr>
<tr>
<td>General Information</td>
<td>8-12</td>
</tr>
<tr>
<td>Our Patient and Carer Opinion Questionnaire</td>
<td>12</td>
</tr>
<tr>
<td>Our Patient and Carer Forum</td>
<td>12</td>
</tr>
<tr>
<td>Have we done what we aimed to do?</td>
<td>13</td>
</tr>
<tr>
<td>Regulation</td>
<td>14</td>
</tr>
<tr>
<td>Booklets available from the Douglas Macmillan Hospice</td>
<td>15</td>
</tr>
</tbody>
</table>
Introduction

This booklet tells you about our Palliative Care Nurse Specialist (PCNS) Service. With information contained in this booklet, we hope that we will answer many of your initial questions. Please let us have your comments on any changes that you think we should make to improve the contents or design.

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can speak to your nurse about this, call us on 01782 344300 or email post@dmhospice.org.uk.

Douglas Macmillan Hospice Community Team

We are a team of specialist nurses who cover North Staffordshire and surrounding areas to provide specialist community palliative care. Each nurse has extensive training, knowledge, experience and expertise in symptom management. We also provide psychological support and give advice to patients and their families on all aspects of their illness.

Each community Palliative Care Nurse Specialist (PCNS) is assigned to a group of GP Practices within the local area. The PCNS will work closely with your GP, community nurses, hospital staff, social services, voluntary organisations, as well as other departments in the hospice.
You may benefit from one of the other services offered by DMH, such as:

- Attending the Day Therapy Unit or Outpatient Clinics
- A stay with our Inpatient Services
- To receive our Hospice at Home Service

In this case, one of our nurses will discuss your needs and provide you and your family with more information about the service.

**What to expect**

Once a referral is received, our first contact will be a 20 minute triage assessment with you to assess your needs and to arrange an appropriate time scale for a PCNS (Palliative Care Nurse Specialist) appointment with you.

The role of the Palliative Care Nurse Specialist is to help you to have the best quality of life possible, for as long as possible. Any decisions about your treatment will be made in agreement with you and your doctor, usually your GP.

Your nurse will talk to you about your illness, how you feel and how it is affecting you and your family. The nurse wants to hear your point of view so they can help you in a way that is right for you as an individual.

The type of approach used by the PCNSs is known as holistic and consists of the following:

- Spending time with you and your family and listening to your concerns. We understand that the emotional, social
and spiritual areas of your life are important, as well as physical symptoms.

- Advising you about any practical issues associated with your illness and signposting you to other services as needed, e.g., District Nurse, about care packages and Occupational Therapy referrals.

- Discussing how you can control pain and any other symptoms you may have. The PCNS will liaise with your doctor about treatments if needed.

Helping you to access other services that may help with support and care.

Your nurse will be open and honest with you and your family, involving you in the planning and delivery of your care. We are happy to answer any questions. If your nurse is unable to answer a particular question, they will refer the question to someone who can help.

Following our telephone Triage assessment, your PCNS will visit you at home, or see you here at our Outpatient Clinic, for a one-off holistic assessment. Afterwards you will be given advice and offered a referral to other palliative care services if needed. However, your PCNS may need to make further appointments to see you until your symptoms are controlled. Thereafter, you will be discharged from our service with a view to being re-referred should the need arise.

All routine visits will be arranged between Monday - Friday, 9am - 5pm, and you will be given a time for the visit. If the staff member is delayed, you will be contacted as soon as possible. There is a PCNS on duty Saturday and Sunday to visit in an emergency situation.

### Planning for your future care

It can be helpful to plan ahead to let people know what your wishes are for your care, particularly if you become unable to make decisions for yourself in the future.

Your PCNS will offer to discuss Advance Care Planning with you, but you are under no obligation to do this until you feel ready.
What Matters To You?

Advance Care Planning is all about giving you the chance to tell others about you and your wishes should you become unwell and unable to tell anyone.

It is a voluntary process and involves a series of discussions that help you explore your personal preferences and choices for your future care and treatment. This will help people involved in your health and welfare like doctors, nurses, family and friends to act in accordance with your wishes.

The Advance Care Planning Service will help you to explore the options open to you. This can include supporting you to:

- Write an Advance Statement
- Write an Advance Decision to Refuse Treatment
- Register Lasting Powers of Attorney

Professionals involved in your care and members of your family may find it helpful if your wishes and preferences are in writing with a copy given to everyone who needs to know. You can also record your wishes verbally. Remember you can change your mind at any time.

General Information

The care of patients who lack mental capacity and are no longer able to make their own decisions

Hospice staff will always act in the best interests of their patient.

Patients will be assumed to have capacity unless there is evidence to show that they lack capacity.

For those patients who do lack capacity and are no longer able to make their own decisions, our staff will help and support patients to make decisions about their own care. In these cases, the Mental Capacity Act Code of Practice will be followed.

The Independent Mental Capacity Advocate (IMCA) Service

Sometimes significant decisions need to be made about treatment or long-term accommodation.

If a patient does not have the capacity to make decisions for themselves, has no friends or relatives and has not made a Lasting Power of Attorney (LPA) authorising someone to make decisions for them, we will contact the local IMCA service.
An independent advocate will act on behalf of the patient, ensuring that decisions are made in their best interests. The IMCA Service in Stoke-on-Trent and Staffordshire is provided by ASIST, telephone number 01782 845584 or visit the website on www.asist.co.uk and select IMCA.

Data Protection and Confidentiality

Douglas Macmillan Hospice (DMH) keeps information about you and the details of the care you received. It is the duty of the DMH to protect the confidentiality of your information. In certain circumstances, we are required to pass this information to other healthcare providers to ensure continuity of care provision.

If you wish to restrict the sharing of your care details with other healthcare professionals, please make this clear to your nurse.

You will be asked to sign a consent form to enable us to obtain information about your medical condition and for us to share information with other relevant Healthcare Professionals, as required.

Some statutory bodies have the legal status that enables them to access patient records for quality monitoring purposes.

Access to Your Health Records

You have a right of access to your own health records (subject to certain regulations). There would be a cost implication should you require your notes to be photocopied. Please ask one of the staff if you require further information.

Private Medical Insurance

If you have private medical insurance please could you let us know as your insurer may wish to make a financial donation to the hospice as a result of the care provided to you.

Personal Budget Holders

If you are in receipt of a personal budget or direct payment for your care needs, please could you let us know.

In certain circumstances, we may request that the relevant part of this budget is used to contribute towards the costs of your care provided by the hospice.

Zero Tolerance

To enable our staff to care for patients in a safe environment, the hospice will not accept any form of aggressive or abusive behaviour towards our staff.

Please be aware that we may need to remove our staff from your home if we consider that they are under threat of any kind.
Information for smokers

It is very important to us that we look after our staff.

Second-hand smoke, or passive smoking as it is sometimes called, has been found to be harmful to people’s health. It can cause heart disease, stroke and lung cancer in adults. Exposure even for a short time can cause eye irritation, headache, cough, sore throat, dizziness and nausea.

“Passive vaping” has been found to occur with e-cigarettes and members of staff need to be protected from e-cigarette vapours (British Medical Association 2012).

Our Policy

Employers have a duty under common law to take reasonable care to protect the health of employees. We are required by the Health and Safety at Work Act 1974 to ensure that employees and others are not put at risk.

How to protect our staff:

• Please refrain from smoking or vaping inside the house for at least one hour before staff arrive.

• Open doors and windows to fully ventilate the home.

• Do not smoke or vape or let anyone else in the house smoke or vape when staff are in the home.

• Please ask smokers to go outside to smoke and keep the door closed; this also applies to vaping.

We ask our staff to assess whether any environment they enter is safe for them. If a smoke-free environment cannot be provided we will support staff’s right to leave.

We ask you to take care of the nurse who takes care of you.

Our Patient and Carer Opinion Questionnaire

At regular intervals, we send out a questionnaire to monitor the opinions of our patients and their carers. Should you receive one of our questionnaires, it would be very helpful if you would complete the form and return it to the address provided.

A copy of the results obtained from our most recent survey is available on request.

Our Patient Forum and our Carer Forum

We have a Patient Forum which discusses how the hospice can best meet the needs of our patients and their carers.

We also hold a Carer Forum to obtain the views of carers about how we can develop hospice services.

Please let your Palliative Care Nurse Specialist know if:

• You are a patient and would like more information about our Patient Forum.

• You are a carer and would like more information about the Carer Forum.
Have we done what we aimed to do?

In this booklet, we have told you about the level of service that we aim to provide. We would greatly appreciate your comments on the level of service that we have provided. It is through your comments that we are able to continue to improve.

If you have any comments, please talk to your PCNS.

What to do if you are unhappy with any aspect of our service.

Please let us know if you are unhappy with any aspect of our service. In the first instance, we ask you to raise your concerns with one of the staff concerned with your care.

If you would prefer to write to us and make a formal complaint, please write to our Chief Executive, at the address given on the front of this booklet.

We will make every attempt to resolve any complaint within 20 working days. If you are unhappy with our response, you may request a referral to our Clinical Governance Committee.

Regulation

The quality of care given by the DMH is regularly monitored by the Care Quality Commission. Periodic inspection reports are available on the Care Quality Commission’s website:

www.cqc.org.uk

You may wish to make a comment, good or bad, to our regulator about the quality of care received. The contact details of the Care Quality Commission are as follows:

Website: www.cqc.org.uk
Telephone: 03000 616161
Email: enquiries@cqc.org.uk
Address: CQC National Contact Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA
The hospice produces a series of booklets, which provide detailed information on the other services that we provide and may be available to you and your family.

- Welcome to the Day Therapy Unit
- Welcome to the Inpatient Services
- Specialist Palliative Care in the Community
- Hospice at Home
- What To Do When Someone Dies at Home
- What To Do When Someone Dies in the hospice
- Social Work
- Spiritual Care
- Your Bereavement

Please ask a member of staff if you would like a copy of any of the above booklets or visit our website: www.dmhospice.org.uk to download a copy.
Further Information

If you would like further information on any healthcare services the following may be of help.

For general enquiries:

- Contact your GP, District Nurse or another member of the Primary Care Team.
- District Nurses Out of Hours 0300 123 0989
- Out of Hours Doctors (non emergency) 111

If you are receiving hospital treatment:

- Contact your hospital Doctor or Clinical Nurse Specialist
- University Hospital North Midlands 01782 715444
- Oncology Ward 201 Emergency Assessment Bay 01782 672444

For general enquiries regarding cancer services:

- Macmillan Cancer Support - 0808 808 0000
- The University Hospital North Midlands Macmillan Cancer Support and Information Centre - 01782 676333 (Disability Solutions 01782 667321)
- Marie Curie Support Line – 0800 090 2309

For enquiries regarding Hospice services in North Staffordshire:

- Douglas Macmillan Hospice’s 24 Hour Advice Line 01782 344300

You may also find the following websites useful:

- www.dmhospice.org.uk
- www.macmillan.org.uk
- www.mariecurie.org.uk
- www.carersuk.org
- www.carersfirst.com
- www.cruse.org.uk
- www.cancerlink.org.uk
- www.nhsdirect.nhs.uk