Specialist Palliative Care in the Community

Douglas Macmillan Hospice
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Registered company number: 3615904
Registered charity number: 1071613
Accessing our Services

Access to any of our Hospice services is by referral from the patient’s GP, hospital doctor or other registered healthcare professional. If you feel that you would like to be referred to the Hospice, please speak to your doctor.

On referral, the patient will receive an arranged visit from a member of our specialist team of community nurses who will carry out a full assessment of needs. As a result of this, options for treatment and access to other parts of the Hospice service will be discussed. For patients already in hospital, the hospital palliative care nurse specialist will carry out this assessment.
Background Information

The Douglas Macmillan Hospice (DMH) opened in 1973. We were one of the first independent hospices in the UK.

We are an independent Hospice providing care for the people of North Staffordshire and surrounding areas; we are not part of any national charitable organisation.

Since opening, we have grown not only in size but also in the extent of the care we offer. Today, the DMH is the only specialist palliative care* provider in North Staffordshire for adults with a limited life expectancy.

None of our patients pay for the care we offer. We rely on voluntary donations to pay for the majority of our costs. As such, we need to raise more than £8 million a year from legacies, grants and donations, fundraising activities, our lottery, and our charity shops.

“Palliative care is the total care of patients whose disease no longer responds to curative treatment, and for whom the aim must be the best quality of life for them and their families.”

– World Health Organisation
Introduction

This booklet tells you about the Hospice’s Palliative Care Nurse Specialist (PCNS) service.

With the 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.

Who are we?

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 PCNSs work closely with your GP, community nurses, hospital staff, Social Services, the voluntary organisations, as well as other departments in the Hospice.
Reasons why you have been referred to the Douglas Macmillan Hospice Community Team

Your GP, hospital doctor or nurse will have decided that you would benefit from receiving the specialist knowledge and experience of our palliative care team.

Usually, the reasons that you have been referred are as follows:

- To advise on the control of symptoms that are causing you problems. These may include such things as pain, nausea, shortness of breath, or constipation.

- To provide psychological support and advice to you and your family.

- Sometimes, the person, who has referred you, thinks that you may benefit from one of the other services offered by the DMH, such as attending the Day Hospice or a stay on the In-Patient Unit in one of our Community Lodges or to receive our Hospice at Home service. If this is so, one of our PCNSs will make the initial contact with you and your family to provide you with more information about the service.
What to expect

Initial telephone contact with you

One of our Palliative Care Nurse Specialists (PCNSs) will contact you within two working days of receiving your referral. This initial contact is by telephone. During the telephone conversation, the PCNS will introduce themselves to you and, with your agreement, make an appointment to visit you. The PCNS will give you their name and contact number should you want to speak to them before the arranged visit or change the appointment.

The initial visit to your home

Unlike the formal uniform worn by Community Nurses, the PCNSs do not wear a uniform. However, they do carry identification with them, which they will show to you.

The PCNSs appreciate that patients and their families may feel anxious about their first visit. They will do all that they can to make you and your family feel comfortable and at ease.

Your PCNS will talk to you about your illness, how you feel and how it affects you and your family. The PCNS wants to hear your point of view so they can help you in a way that is appropriate for you as an individual.
The PCNS will discuss with you ways in which your quality of life may be improved. With your agreement, the PCNS may need to liaise with the other professionals to discuss changes to your medication or care. At all times, we will respect the choices that you make regarding your care.

If appropriate, at the end of the visit, the PCNS will arrange a suitable date and time to contact you again. We will try to make sure that you see the same PCNS on each visit. However, this may not always be possible.

**Our undertaking to you**

All routine visits will be arranged and you will be given a time for the visit. If the staff member is delayed, you will be contacted as soon as possible. Visits are normally Monday to Friday, 9.00 a.m. to 5.00 p.m.

**24 Hour Advice Line**

Patients and their carers can access our 24 hour advice service. Your call will be taken by our Palliative Care Nurse Specialists, who will be happy to give you advice and support. If required, for more complex issues, the nurse has access to our on-call medical team.

The 24 hour advice service provides telephone contact only. We do not provide a 24/7 visiting service. The number to ring is (01782) 344300.
What kind of care does the Palliative Care Nurse Specialist provide?

The role of the Palliative Care Nurse Specialist (PCNS) is to look at what is needed to promote and maintain the best quality of life possible, for as long as possible. However, the decisions about your treatment will be made in agreement with your doctor, usually your GP.

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

- Spending time with patients and their families and listening to their concerns. The PCNS understands that the psychological, social and spiritual needs of patients should be discussed.

- Advising patients about the practical issues associated with their illness.

- Discussing with patients how they can control their pain and other symptoms. The PCNS will liaise with your doctor, as necessary.

- Helping patients to access the other services, which may help with support and care.

The PCNS 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 PCNS is unable to answer a particular question, they will refer the question to someone who can help. However, we understand and respect that some patients would prefer not to ask any questions.
Planning for your future care

You may want to take the opportunity to think about what living with a serious illness might mean to you, your partner or your relatives, particularly if you become unable to make decisions for yourself. You may wish to record what your preferences and wishes for future care and treatment might be or you may simply choose to do nothing at all.

One way of making people aware of your wishes is by a process of advanced care planning. This is a process of discussion between you and those who care for you, for example nurses, doctors, care home manager, or family members. Not everyone will want to engage in such a conversation and that is fine.

Advanced care planning can occur at any time you choose.

The wishes you express are personal to you and can be about anything to do with your future care, for example:

- How you might want any religious or spiritual beliefs you hold to be reflected in your care.

- The name of a person/people you wish to act on your behalf at a later time.

- Your choice about where you would like to be cared for, for example, home, in hospital, nursing home or hospice.
• Your thoughts on different treatments or types of care that you might be offered.

• Concerns or solutions to practical issues for example who will look after your dog should you become ill.

You may have a very specific view about a particular treatment that you do not wish to have. This can be done by making an advanced decision to refuse treatment. You are advised to discuss this with a health care professional who is fully aware of your medical history. The advance decision will only be used if at some time in the future you lose the ability to make your own decisions about your treatment.

You may wish to name someone, or more than one person, to speak on your behalf if you are not able to make decisions yourself. This person can be a close family member or friend. If in the future you are unable to make decisions for yourself, a health or social care professional would if possible consult with the person named to provide information about your wishes, feelings and values. This would help the health care professional to act in your best interests. This is not the same as legally appointing someone to make decisions under a lasting power of attorney. More information on making a lasting power of attorney is available from the Office of the Public Guardians. 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.

Remember you can change your mind at any time.
Information for people who Smoke

Second-hand smoke, or passive smoking as it is sometimes called, has been found by the Government Scientific Committee on Tobacco and Health to be detrimental 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 in common law to take reasonable care to protect the health of employees. The DMH is required by the Health and Safety at Work Act 1974 to ensure that employees and others are not put at risk.

How to protect staff from exposure to second-hand smoke

- 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 to provide their services. If a smoke-free environment cannot be provided we will support staffs’ right to leave.

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

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**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 their best interests of the patient.

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

For those patients who lack capacity and are no longer able to make their own decisions, 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 the best interests of the patient. 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.

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 at 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.

Confidentiality

The 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 professional, please make this clear to your nurse.

You will be asked to sign a consent form for 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 Own 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.
Other services available to you and your family

The Hospice produces a series of booklets, which provide detailed information on each of the services that we provide.

Please tell your PCNS if you would like a copy of any of our booklets.

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 identify if there is some shortfall in our service.

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
Our patient and carers 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 us.

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

Our Patients’ Forum and our Carers’ Forum

The Douglas Macmillan Hospice has a Patient’s Forum, which discusses how the Hospice can best meet the need of patients and their carers.

The hospice holds a Carers Forum monthly to obtain the views of carers about how we can develop hospice services.

Please let you Palliative Care Nurse Specialist know if

- You are a patient and would like more information about the Patient’s Forum.
- You are a carer and would like more information about the Carers’ Forum.
Booklets available from the Douglas Macmillan Hospice

- General Information
- Welcome to The Day Therapy Unit
- Welcome to the In-Patient Unit
- Specialist Palliative Care in the Community
- Welcome to the Community Lodges
- Hospice at Home
- What to do When Someone Dies at Home
- What to do When Someone Dies in the Hospice
- Social Work
- Spiritual Care
- Bereavement Support
Further Information

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

DMH 24/7 Advice Line 01782 344300

For general enquiries relating to health services
• Contact your GP or District Nurse - 0300 123 0989
• Out of Hours Urgent Care (non-emergency) - 111

If you are receiving hospital treatment
• Contact your hospital doctor or clinical nurse specialist
• Royal Stoke University Hospital - 01782 715 444

For general enquiries regarding cancer services
• Telephone Macmillan Cancer Support on 0808 808 00 00
• The UHNS Macmillan Cancer Support and Information Centre on 01782 676 333
• Marie Currie Support Line - 0800 090 2309

You may also find the following websites useful:
• www.carersuk.org
• www.cruse.org.uk
• www.mariecurie.org.uk
• www.macmillain.org.uk
• www.carersfirst.com