



Northern Health
and Social Care Trust

Palliative and End of Life Care Services

For you, your family and carers





About palliative and end of life care:

This booklet has been written for you, your family and carers. It explains what is meant by the term 'palliative and end of life care'. It also provides useful information about the range of health and social care professionals who deliver palliative care services and the support they can offer. It may help to discuss this information together after you have read it and decide which professionals can support you in your own home or in hospital.

It is not always easy to ask for help as people often feel they should try to cope alone. Many support services can help you deal with any problems that you face. It is important that you, your family and those close to you have as much support as possible, as coping by yourselves can be hard work.

At the end of this booklet there are website links to a range of other organisations that can help you, your family and those close to you find the unique support for your needs.



What is palliative and end of life care?

Palliative care is offered when it is clear an illness is no longer curable. Examples of such illnesses include advanced cancer, heart or lung disease, kidney failure, dementia, and motor neurone disease to mention a few.

Palliative care can help manage your symptoms and help with any emotional, social, financial, practical or spiritual needs you or those people close to you may have. Palliative care can be provided for years, with some people having long periods of being well, moving in and out of palliative care services, depending on their needs. Palliative care may be provided alongside treatments, therapies and medicines aimed at controlling your illness and improving your quality of life. You can receive palliative care at home, in hospital, in a care home or in a hospice/ specialist palliative care unit.

End of life care is a key part of palliative care. Identifying when a person is approaching this stage can be difficult to predict. Some people may prefer to focus on their needs and how these may change rather than knowing a time scale. Health care professionals will assess your needs so that the right care can be provided for you at the right time. This allows you to plan ahead for your preferences and wishes.

There are many people involved in providing palliative and end of life care services. Good communication is important between you, your family and the services to ensure that your needs are met.

GP

Your GP has overall medical responsibility for your care while you are at home and can refer you to other professionals to help with any problems you may have. You can talk to your GP about all the options for treating your illness and managing symptoms or any aspect of care that you may be worried about.

If you need medical advice or care out of hours, which cannot wait until your own doctor's surgery is open, see the 'contacts section' on page 19.

If you have been assessed as needing home oxygen this can be arranged and prescribed by your own GP, or on some occasions the community respiratory team. This will be monitored and reviewed by your health care professional.

There are GP managed palliative care beds for those with less complex needs in Inver Intermediate Care Unit in Larne, Dalriada Community Hospital in Ballycastle, Robinson Community Hospital in Ballymoney and Mid Ulster Hospital in Magherafelt. The Hospital Specialist Palliative Care Team can also provide support within these community hospitals, see page 10.

District Nursing

The District Nurse will generally be your identified palliative care key worker and will coordinate your care at home. District Nurses are experienced community nurses who work closely with the GP. Where appropriate, they will link with other professionals and services depending on your individual needs. District Nurses will also assess if you need any nursing equipment to help you manage at home.



This service is also focused on providing support and practical advice for your family and carers on how they can help in your care. The District Nurse will ask your permission to record your details on a Trust palliative care register. This will support and prioritise the coordination and planning of your care. If you need to contact the District Nursing service, see page 18 for details.

Hospital Diversion Nursing Team (HDNT)

The HDNT are an extension to the District Nursing service. Your District Nurse can arrange a planned visit by the HDNT to you after 5pm to assist with your nursing care needs. If you have urgent care needs out of hours, you can access the team via Dalriada Urgent Care. They work from 8.45am – 10.45pm.

HDNT may also be able to administer intravenous antibiotics or blood transfusions to you in your own home or at clinic, if this has been pre-arranged with your doctor.

Social Worker

Social Workers are trained to support people and their families during difficult times in their lives, which includes dealing with a serious illness. They can help you think about areas you want support with and then look at the available options.

Support can be:

- Practical eg. managing personal care, checking your finances, helping you keep children informed, making arrangements for the future, getting your affairs in order.
- Emotional eg. dealing with the effects of illness on you, your family and your relationships.



- Social eg. housing, keeping up your interests, having enough company.
- Spiritual eg. what's important to you, your beliefs.

Social workers assess, arrange and provide support and information themselves but also link with other staff and services to make sure you have the assistance you need. Referrals are made via any health care professional including GP involved in your care. If you are over 65 years you can also refer yourself to your local team.

Physiotherapist

Physiotherapy aims to help you maintain or improve independence. This can reduce dependence on family and carers, encourage the use of self-management techniques and give you a sense of control through achieving your goals. The physiotherapist also plays an important role in management of symptoms such as pain, breathlessness, fatigue and lymphoedema. They will assess your mobility and provide walking aids as and when required. A physiotherapist can also provide individualised exercise programmes aimed at improving muscle strength and mobility, whilst managing your advancing illness. Referrals can be made by any health or social care professional involved in your care.



Occupational Therapy

Occupational Therapy aims to help you with everyday activities eg. getting dressed, managing the bath/shower or stairs, leisure activities, helping you to get out and about. The Occupational Therapist can look at what tasks you want or need to do and



what makes this difficult for you. Intervention may include teaching new ways of doing activities, providing equipment or adaptations, information and advice on managing symptoms such as fatigue, breathlessness and anxiety or referring to other professionals, e.g. for practical support. Referrals can be made by any health or social care professional involved in your care.

Depending on your condition you may also be referred to other specialist services such as the respiratory or heart failure nurse.

Speech and Language Therapy

Speech and Language Therapy (SLT) aims to help you with communication and swallowing difficulties:

- Communication intervention: this may include helping you to find a way to communicate as independently as possible in order to maintain personal relationships and facilitate your involvement in discussions around your care. It may involve advice regarding strategies and/or provision of an alternative communication system.
- Swallowing intervention: the SLT can be involved in the management of swallowing difficulties in order to maximise your comfort, safety and pleasure in eating and drinking.



Referrals can be made by any health or social care professional or directly by yourself. More information can be found: <http://www.northerntrust.hscni.net/services/speech-language-therapy/adult-speech-and-language/>

Dietitian

The role of the palliative care dietitian includes carrying out a nutritional assessment to provide advice tailored to meet individual specific needs. The priority for nutrition in palliative care is to promote the enjoyment of food, quality of life, comfort and symptom management. The dietitian can help you and your family make informed choices regarding your diet. Maintaining a good nutritional status can help to retain physical strength to prolong independence. Referrals are made via your District Nurse or GP.



Pharmacy

Supporting people with palliative care needs often involves the use of medicines. Everyone's needs are different, but medicines may be useful to help manage your symptoms.

Medicines can be administered by lots of different routes. These can be by the mouth or under the tongue, through injections, pumps, drips, or applying them on the skin. Your particular symptoms and individual circumstances, will guide what medicine you get and how you take it.

Sometimes if there are several medicines it can become confusing about what to take and when. If you have any questions about medicines you can ask your doctor, nurse or pharmacist for advice.

Further information about medicines for patients with palliative care needs can be found at: <https://pcip.hscni.net/what-is-palliative-care/information-for-people-carers-and-relatives/palliative-care-medications/>



Marie Curie Nursing Service

Marie Curie Nurses and Health Care Assistants provide nursing care and support to people in their own homes. They provide a range of services based on individual need and availability.



They work closely with the District Nurse with the aim of providing the care that is right for you when you need it most. Their planned nursing services offer overnight care and shorter periods of care during the day. Each visit may vary in length depending on your individual care requirements. Referrals are made via your District Nurse.

Marie Curie Rapid Response

If you need urgent nursing support or advice out of hours you can contact a Marie Curie Nurse through the Dalriada Urgent Care Out of Hours service on 028 2566 3500, see page 18 for further details.

Marie Curie Helper Service

The Marie Curie Helper service is a one-to-one support service for anyone who has an advanced, life limiting illness. The service aims to support you as well as those who are caring for you and is tailored to meet your individual support needs. A Marie Curie Helper helps with companionship and social support rather than nursing or medical care. Referrals can be made by any health or social care professional or directly by yourself.

Tel: 07740456750 (9am – 5pm, Monday to Friday)

Email: nihelper@mariecurie.org.uk

Website: www.mariecurie.org.uk/helperservice

Hospice at Home Nursing Service

The Hospice at Home Service provides nursing care at home for you as well as practical and emotional support and respite for your family and carers. It allows your carers to have a break, either during the day and early evenings or, if necessary, at night. Referrals are made via your District Nurse.

Macmillan Community Helpers Scheme

This is a volunteer-led service providing practical and emotional support to adults affected by cancer. These trained volunteers can make a huge difference by providing help tailored to individual needs.

Support can include: light housework or gardening, walking the dog, shopping or running errands, having a chat and signposting to other relevant services. Volunteers will not be able to help with personal care.

For further information about availability in your area, or to make a service request for yourself or someone you know affected by cancer, contact the Volunteering Team on 028 9070 8610 or email dvsni@macmillan.org.uk

Specialist Palliative Care Services

On occasions some people with an advanced life limiting illness and complex symptoms require help from the Specialist Palliative Care Teams. This service is available to people in their own homes, care homes or hospitals and works alongside the general doctors, nurses and other team members.





**Northern
Ireland
Hospice**

- **Northern Ireland Hospice Community Service**

In the community specialist palliative care is provided by the Northern Ireland Hospice. Specialist nurses with advanced qualifications and experience in palliative care work across local areas providing care through outpatient clinics or visiting you in your own home.

They complement the care provided by the GP and District Nurse by providing specialist advice and support to try to enable you to remain in your preferred place of care, whilst supporting your family. Referral to this specialist advisory service is via your GP or District Nurse.

- **Macmillan Specialist Palliative Care Team**

**MACMILLAN
CANCER SUPPORT**

In the hospital setting specialist palliative care is provided by a team of Macmillan nurses and doctors who have advanced qualifications and experience in symptom management within palliative care. They can provide support, information and advice to you and your family. They can also provide support to your medical and nursing teams should your needs become more complex whilst in hospital. Specialist palliative care includes assessment and management of physical, emotional, social and spiritual issues. They also liaise closely with other staff in the hospital and community to ensure that the appropriate services are in place for discharge. Referral to the team is via the ward staff.

- **Palliative Medicine Consultant**

Palliative Medicine Consultants are senior doctors with specialist training in palliative medicine, including symptom control and end of life issues.

They are an essential part of both community and hospital specialist palliative care teams. The doctors meet regularly with the specialist palliative care teams to discuss and advise on your care. If you have complex needs,



“To deliver excellent integrated services in partnership with our community”

they can make arrangements to visit you in hospital or at home. If appropriate you can also be seen on an outpatient basis. Referral to the Palliative Medicine Consultant is via your Hospice Nurse or GP.

- **Specialist Inpatient Units**

Specialist inpatient units provide a range of care for adults with complex specialist palliative care needs. They focus on enhancing quality of life and offering support for all areas of your life affected by your illness. There are two specialist inpatient units available to people who live in the Northern Trust; these are the Macmillan Unit, Antrim and the Northern Ireland Hospice, Belfast. A specialist multidisciplinary team contributes to the holistic approach to care. In addition to the medical and nursing support this team includes a social worker, physiotherapist, occupational therapist, dietitian, chaplain and pharmacist. Volunteers provide a valuable range of activities to complement the work and purpose of the specialist service. Referrals to the specialist unit is via your specialist nurse or doctor in charge of your care, if your needs are complex.

- **Hospice Hub**

The Northern Ireland Hospice, Belfast has a day well-being clinic known as the Hospice Hub. It aims to treat the symptoms of your illness as early as possible and/ or any psychological, social or spiritual problems that you may be experiencing. At the Hospice Hub, you can be assessed by one of the team and a programme of care will be developed to meet your needs. This may be done through individual appointments with members of the team or in a group setting through the well-being programme, which is a six week programme led by the multidisciplinary team. The team aim to improve your overall well-being at a time in your life when you may be adjusting to your illness. This well-being clinic is available every Tuesday in Belfast, Thursday in Ballymoney, with individual clinics on Wednesday's and Thursday's in Belfast.



On a Friday, the Hub in Belfast holds a well-being clinic for people with dementia and their carers. At this clinic the focus is on holistic care with an aim to promote quality of life. Referrals can be made by any health or social care professional.

Spiritual care and chaplaincy

Having a palliative illness can affect you in many different ways and this includes spiritually. How you express your spirituality is unique to you – it may be through music, the arts, sport, relationships, nature, your faith or a combination of these and other ways.

No matter what spirituality means to you, it is always good to recognise that caring for your spiritual needs is just as important as caring for your physical well-being. We all need someone to listen to our fears, desires, hopes and doubts. As well as other health and social care professionals, chaplains can play a key role. They are skilled, non-judgemental listeners for all; whether you have a faith background or not. They are able to signpost you to various resources regarding your spiritual care. If in hospital or hospice why not ask the team to arrange for you to see a chaplain.



Finances and Benefits

Illness can affect you financially. For example, you or those close to you may need to stop working, or work less. It can also mean spending more money on things like heating, clothing, hospital parking etc. Financial problems can feel complicated and intimidating. Depending on your situation, you may be able to get benefits or other financial and practical support. There are organisations that can help with free, confidential and independent advice and support. They can also help with other concerns such as debt, housing, and employment.

If you have a cancer condition, contact;

- Macmillan Benefits Service: Tel: 0300 1233 233 Option 1

For any palliative condition, contact Community Advice

- Causeway: Tel: 028 7034 4817
- Antrim & Newtownabbey: Tel: 028 9590 6505
- Mid & East Antrim (Larne, Carrick and Ballymena)
Tel: 028 9600 1333



Support for Family and Carers

If there is someone at home who looks after you or helps to look after you, the Northern Trust Carer Hub can provide information, signposting and support for them in their role as ‘carer’.

Occasionally family carers can worry, or become stressed about caring for their loved one. The Trust’s Carer Hub therefore provides a range of support to help carers manage their caring role and any worry that’s associated with it. Support includes connecting with other carers, providing classes to help while caring and sharing information on what can be available.



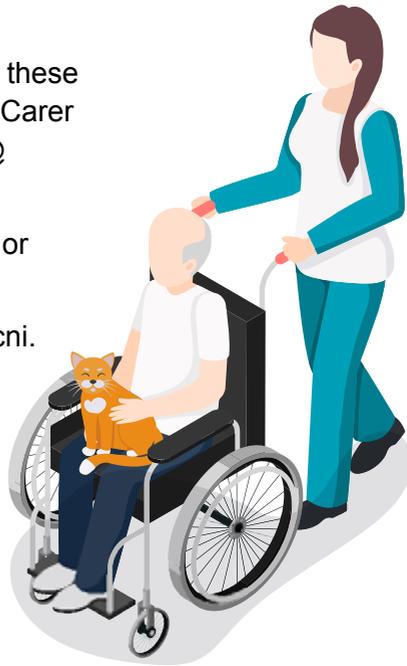
In particular:

- Access to the Carer Support Programme which includes training and support for carers in issues such as, basic first aid, good nutrition, pilates, complementary therapies etc.
- Information on how to receive a Carers assessment with your named worker, to enable the Trust to establish support needs of carers.
- Provide a Carer Support and Welcome Pack containing a variety of leaflets, carers newsletter, support programme and directories providing written practical advice, and contact details of other support organisations.
- Information of support available for young carers (young people aged from 8 – 18 who help to provide care for a sick relative), by Barnardo's Young Carers Service.

For further information about these support services contact the Carer Hub by emailing: carer.hub@northerntrust.hscni.net

or telephone 028 2766 1210 or Trust web page:

<https://www.northerntrust.hscni.net/services/carerrhub/>



Support for Children

Children of all ages will cope differently when someone close to them is ill. It is important to involve them and talk with them about what is happening in a way that is suitable for their age. This can be difficult and as parents or someone caring for a child you may feel that by not telling them you are protecting them. Trying to protect children from difficult news, worry and distress is natural. However, often children know when something serious is affecting the family, they will be aware of changes in the home and in the adults around them. Not explaining what's happening may make them feel more vulnerable and anxious. Talking openly with your children about the situation gives them a sense of feeling secure, less scared or anxious. You can reassure your children that they can trust you to be honest with them and that they can ask you any questions. For further reading and advice, visit Marie Curie online:

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/individual-needs/telling-children-and-young-people>

<https://www.mariecurie.org.uk/blog/parents-talk-child-death/320773>.

Marie Curie Support Line contact is 0800 090 2309, a trained professional will be at the other end of the phone to help you with any questions you may have.



Bereavement Support

The Trust acknowledge bereavement can be a difficult time for family and friends. Your hospital nurse or District Nurse can provide a bereavement information pack containing essential information on practical next steps, grief and bereavement and support organisations.

If you feel you could benefit from further information on bereavement support organisations, this can be found on the Trust webpage:

<https://www.northerntrust.hscni.net/services/bereavement-services/>

Alternatively, your GP can provide support and further advice.

Organisations that can help

Health and social care professionals involved in your care can refer you to a wide range of other services according to your needs, such as counselling support, benefits advice, carers' support etc.

Also, a range of information on services can be accessed through the following links/ contacts:

<https://www.northerntrust.hscni.net/services/palliative-care/>

<https://pcip.hscni.net/>

<https://www.hospiceuk.org/>

<https://aiihpc.org/>

www.compassionatecommunitiesnw.com



Useful Contacts:

Job Title	Role	Contact Number
District Nurses (D/N)	<ul style="list-style-type: none"> • Will assess, monitor, support and visit as agreed • Will act as Key Worker to co-ordinate your care to meet your needs • If needed will check and fill your syringe driver • Will keep close contact with your GP and other professionals involved in your care • If needed, can arrange additional nursing equipment or services 	Contact them, if needed, through your GP or 'Call Management': 028 2563 5521 (9 – 5pm, Mon – Fri)
Out of Hours Nurse (Marie Curie) (Through Dalriada Out of Hours service)	<ul style="list-style-type: none"> • Provide advice and support on any issues that maybe worrying you eg. issues with syringe driver, or troublesome symptoms 	028 2566 3500  Night time support (5.30pm – 8am Mon-Fri) (full 24 hour cover) at weekends & public holidays



Job Title	Role	Contact Number
GP's Out of Hours service (Through Dalriada Out of Hours service)	<ul style="list-style-type: none"> • Contact them about any urgent medical problems at night, weekends etc • Experienced staff will give you appropriate advice. 	028 2566 3500  Night time support (6 pm – 8 am), all weekends & public holidays
Equipment repair line	If your equipment which was provided by the NHSCT doesn't work contact the Estate Services Action Desk.	028 9441 3694 (9am – 4.45pm, Mon – Fri). Outside of these hours the call will be redirected in an emergency
Returning equipment	Contact community nurse, OT, physio or telephone the community equipment centre to return NHSCT equipment when it is no longer needed.	028 2563 3985 Option 1 (8.30am – 4.30pm Mon- Fri)

Other Information:



INVESTORS
IN PEOPLE

Accredited
Until 2021

Our Vision

To deliver excellent integrated services in partnership with our community

Thank you for taking the time to read this booklet and we hope you have found the information within it helpful

www.northerntrust.hscni.net

If you would like to give feedback on any of our services please contact:

Email: user.feedback@northerntrust.hscni.net

Telephone: 028 9442 4655



Northern Health and Social Care Trust



@NHSCTrust

www.northerntrust.hscni.net



This information is accurate at time of printing

Review Date: 2024