Palliative and End of Life Care Services

For you and Your family/carers
About palliative and end of life care:

This booklet explains what is meant by the term ‘palliative and end of life care’ and gives you, your carers and close friends information about relevant services.

Both you and your carers can read this booklet as it explains the different roles that health and social care professionals have in delivering palliative care services. It may help to discuss this information together after you have read it and decide which professionals can help 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 cope at what may be a difficult time. It is important, that you and your family/carers have as much support as possible, as coping by yourselves can be hard work.

At the end of this booklet there is a website link to a range of other organisations that can help you and your family/carers find the unique support for your needs.
What is palliative and end of life care?

Palliative care is the care available to people whose illness can no longer be cured. It is about achieving the best quality of life for people with advanced, life-limiting diseases such as cancer, heart or lung disease, kidney failure, dementia, stroke and other conditions like motor neurone disease and multiple sclerosis.

End of life care is an integral part of palliative care, focusing on the last year or less of life. It enables the palliative care needs of both patient and family to be identified and met throughout the last phases of life and into bereavement.

There are many people involved in providing palliative and end of life care services. Good communication and teamwork is important between you, your family and the services to ensure that your needs are met.
GP
Your GP has overall 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 doctor 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 urgent advice or care out of hours which cannot wait until your own doctor’s surgery is open, you can telephone Dalriada Urgent Care on 028 2566 3500. Experienced staff will give you appropriate advice. This service is available from 6pm to 8am Monday to Friday and there is on-going cover at weekends and on public holidays.

There are GP managed palliative care beds in Inver Intermediate Care Unit in Larne, Dalriada Community Hospital in Ballycastle and Robinson Community Hospital in Ballymoney. The Hospital Specialist Palliative Care Team can also provide support within these community hospitals.

District Nursing
District Nurses are experienced community nurses who work closely with the GP. The service is based around care at home and provides a range of nursing care and support based on an assessment of your individual needs. District Nurses will also assess for provision of any nursing equipment you may need to manage at home.

The service is also focused on providing support and practical advice to your family and carers on how they can help in your care. The District Nurse will generally be your identified palliative care key worker and will coordinate your
care at home and where appropriate link with other professionals and services depending on your individual needs. 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.

Hospital Diversion Nursing Team (HDNT)
This service aims to prevent admission to hospital. It helps to get you home sooner and can also help reduce attendance at the emergency department.

This team provides services to people with acute health care needs, for example, intravenous antibiotics or blood transfusions in their own homes.

Social Worker
Social Workers are trained to support individuals and families during difficult times in their lives, including serious illness. They can help you identify areas you would like assistance with and to look at choices/ options available to you. Areas include practical issues (e.g. managing personal care, assistance with finances), emotional issues (e.g. dealing with the effects of illness on you, your family and your relationships), social issues (e.g. housing, keeping up your interests) and spiritual issues (e.g. your beliefs on life). 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.
**Physiotherapist**
Physiotherapy aims to help improve or maintain your physical ability to help you achieve goals. Your physiotherapist will play an important role in helping you to manage breathlessness; they will assess your mobility and provide mobility aids, specific and tailored exercise programs, pain management techniques and advice on lifestyle management.

**Occupational Therapy**
Occupational Therapy aims to help you with everyday activities e.g. getting dressed, managing the bath/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 aids, 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.

You may also be supported by other services such as the speech and language therapist or dietician. Depending on your condition you may also be referred to other specialist services such as the respiratory or heart failure nurse.

At home the GP and community nursing service are the main providers of your care. They are also supported by additional palliative care services depending on your needs, which are assessed and referred by the District Nurse.
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 24 hours a day, seven days a week based on individual need.

They work closely with the District Nurse with the aim of providing the care that is right for you when you need it most. Each visit may vary in length depending on your individual care requirements. Referrals are made via your District Nurse.

Marie Curie Out of Hours Nursing Service
If you need urgent advice or care out of hours you can contact a Marie Curie Nurse through the Dalriada Urgent Care Out of Hours service on 028 2566 3500. This service is available from 10pm to 8am seven days a week and 8am to 10pm at weekends and public holidays.

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.

Marie Curie Helper Service
The Marie Curie Helper Service is a one-to-one support service for anyone who has an advanced progressive illness. This 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 does not provide any nursing or medical care or advice.
Referrals are welcome from any health or social care professional. Families who need our service can make contact directly for support.
Tel: 028 9088 2078 (9am – 5pm, Monday to Friday)
Email: NIhelper@mariecurie.org.uk
Website: www.mariecurie.org.uk/helperservice

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

**Community Specialist Palliative Care Team (Northern Ireland Hospice)**
Specialist palliative care in the community is provided by the Northern Ireland Hospice. Specialist nurses with advanced qualifications and experience in palliative care work across local areas 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. You should speak to your GP or District Nurse if you wish to access this service.

**Palliative Medicine Consultant**
Palliative Medicine Consultants are 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.
They meet regularly with the teams to discuss and advise on your care and can make arrangements to visit you in hospital or at home if necessary if you have complex needs. If appropriate, you can also be seen on an outpatient basis.

**Hospital Specialist Palliative Care Team (Macmillan)**

In the hospital setting within Northern Trust 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 will provide support, information and advice to you, your family and to the 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. You should speak to the ward team if you wish to access this service.

**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 in-patient units available to people within the Trust; these are the Macmillan Unit, Antrim and the Northern Ireland Hospice, Belfast. A specialist multidisciplinary team contribute 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. To compliment this specialist service, volunteers provide a highly valued input to the ethos of care through a range of activities. You should speak to the doctor in charge of your care or palliative care nurse specialist if you wish to access this service.
**Day Hospice**
Day Hospice offers you the opportunity to take advantage of a range of therapies and services allowing you to meet people, share experiences and take part in new activities. Day Hospice aims to help you manage your symptoms and gain more confidence at home to help improve your quality of life. Day Hospice is available Tuesday, Wednesday and Thursday in Belfast and Thursday in Ballymoney. You should speak to any health care professional that is involved in your care if you wish to access this service.

**Support for Family/ Carers**
If there is someone at home who looks after you or helps to look after you, the Northern Trust can provide support for them in their role as ‘carer’.

Occasionally family carers can worry, or become stressed about caring for their loved one. The Trust therefore provides a range of support to help carers manage their caring role and any worry that’s associated with it. In particular:

- Training/support for carers in issues such as medication management, basic first aid, personal care, good nutrition, complementary therapies etc.
- Local carer support groups, providing a chance to family carers to meet together.
- Carers assessment, to enable the Trust to establish support needs of carers.
- Small grants that can be used for complementary therapy, extra respite, travel expenses etc.
• A dedicated telephone helpline providing benefits advice, run by Carers Northern Ireland.
• A range of leaflets/directories providing written practical advice, and contact details of other support organisations.
• Targeted support for young carers (young people aged from 8 – 18 who help to provide care for a sick relative), provided by Barnardo’s Young Carers Scheme.

For further information about these support services contact the Carers Co-Ordinator by telephone: 028 2766 1377 or email: carers.coordinator@northerntrust.hscni.net

www.northerntrust.hscni.net

Bereavement Support
If you would like further information on bereavement support organisations, this can be found on the Trust webpage www.northerntrust.hscni.net
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:

www.northerntrust.hscni.net

www.pallcareni.net/informationservices/networksservices
Use the list below to record names of professionals involved with your care.

**Useful contacts**

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Other information
Our Vision

To deliver excellent integrated services in partnership with our community

If you would like to give feedback on any Northern Trust services please contact:
Email: user.feedback@northerntrust.hscni.net
Telephone: 028 9442 4655

Northern Health and Social Care Trust

www.northerntrust.hscni.net

This document is available, on request, in accessible formats including Braille, audio and minority languages.

Our Values

COMPASSION
OPENNESS
RESPECT
EXCELLENCE