

Do you look after someone with palliative care needs?

Carers information pack

This leaflet has been reviewed in partnership with:



1. Introduction

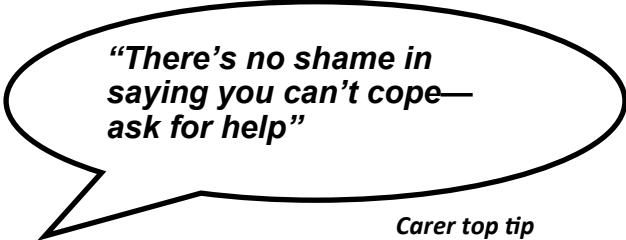
This leaflet has been designed to provide information to family members, relatives and friends (often known as carers) looking after someone with a life limiting illness.

Carers have been involved in putting together this information for you.

It will:

- Help you gain a better understanding of palliative care and the professionals that may be involved in providing support to you and the person you care for
- Help you think about your role as a carer and support which could help you.
- Provide information about other support that is available include some top tips from carers who have been through similar experiences.

A life limiting illness may be unpredictable, and as a carer you play an important role in helping the person you care for through their illness. Being a carer can be an extremely rewarding experience but there are times when you may feel stressed and lonely and may need support yourself. Everyone is different and we encourage you to choose the help and support that is right for you and the person you care for.

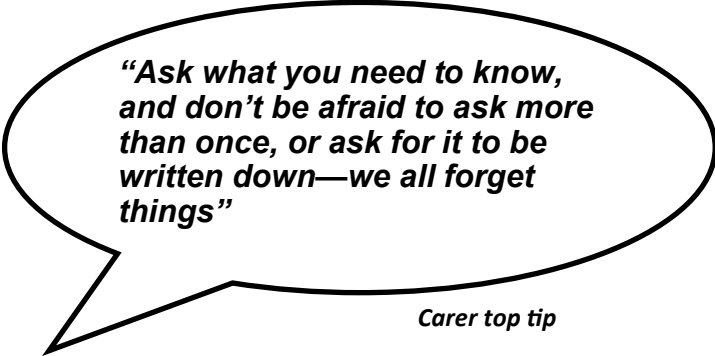


“There’s no shame in saying you can’t cope—ask for help”

Carer top tip

2. What is palliative care?

Palliative care is the care and support of people with a serious progressive illness that cannot be cured. This illness could be cancer, advanced neurological disease, or poor function of important organs such as the heart, lungs or kidneys. Palliative care can also include support for you and your family in your caring role. This type of care helps the person you care for with their individual care needs, quality of life as well as managing symptoms during their illness and at the end of their life.



“Ask what you need to know, and don’t be afraid to ask more than once, or ask for it to be written down—we all forget things”

Carer top tip

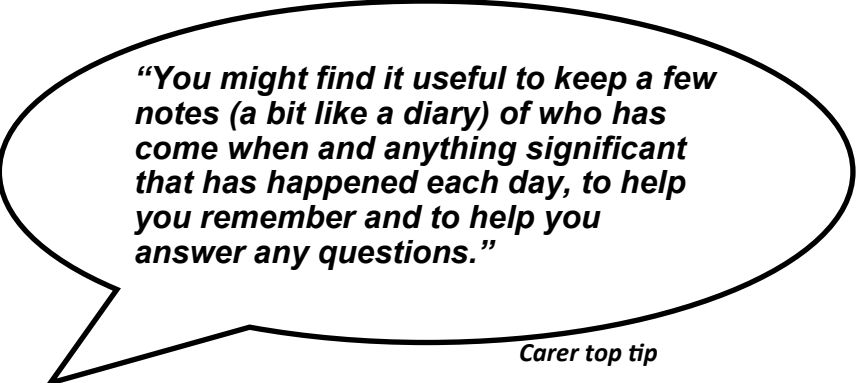
3. Who provides Palliative Care?

Palliative care is provided by your usual professionals including district nurses, family doctor (GP), hospital doctors and nurses, care home nurses, physiotherapists, occupational therapists, social workers and care workers. Palliative care is provided by a team of these professionals who will work together with you as a carer.

They are there to support the person you care for to be as comfortable as possible, to help them choose where they are cared for e.g. at home, care home, hospice or hospital. Their aim is to help ensure the person you care for has the opportunity to die in their preferred place of care with dignity.

Sometimes your doctors and nurses think that you and the person you care for may benefit from extra support and help from a specialist in palliative care.

They will discuss this with the person you care for and you and then may make a referral to the specialist palliative care service if this is what the person you care for and you want.



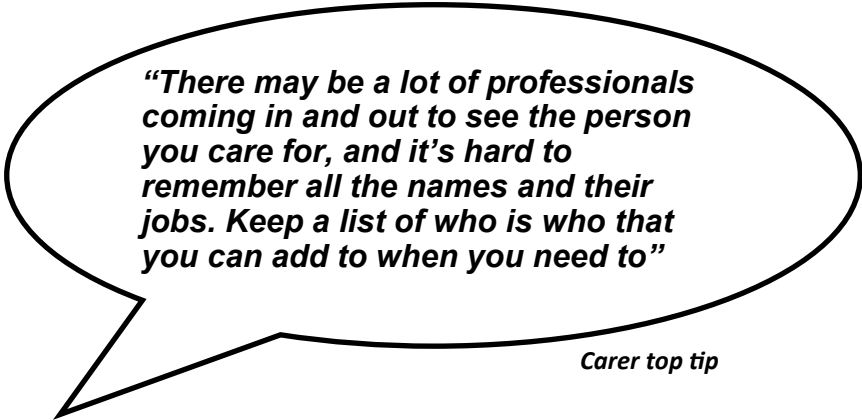
“You might find it useful to keep a few notes (a bit like a diary) of who has come when and anything significant that has happened each day, to help you remember and to help you answer any questions.”

Carer top tip

4. Palliative care at home and who provides it?

Palliative care is provided at home by GPs, community nurses and/or care home nurses, as well as physiotherapists, occupational therapists and social workers. They will keep in close contact with hospital doctors and nurses.

The GP has a register of very important patients (VIPs) with the greatest health needs. This list may be called the '*palliative care register*'. The register helps doctors and nurses to focus on improving the quality of life for the person you care for, ensuring good symptom control, support and help for you as a carer. The GP Practice will regularly discuss the care of the person you care for as a team and may add information to their records so that everyone is aware of their priority status when they or you contact them. The GP may wish to also share information with the out of hours GP services and the ambulance service to support the care that the person you care for gets.



“There may be a lot of professionals coming in and out to see the person you care for, and it’s hard to remember all the names and their jobs. Keep a list of who is who that you can add to when you need to”

Carer top tip

5. What is specialist palliative care?

Specialist palliative care:

- provides advice and support on complex symptoms that may be of concern to you and the person you are caring for, and the opportunity to discuss thoughts and feelings.
- offers advice and support to the person you care for, you and your family if they would like it.
- may advise on symptoms and give support at the end of life.

Specialist palliative care professionals:

- provide advice and support on complex symptoms that may be of concern to the person you're caring for and the opportunity for them to discuss their thoughts and feelings.
- offer advice and support to you in your caring role and your family if you would like it or need it?
- may advise on symptoms and give support at the end of life.

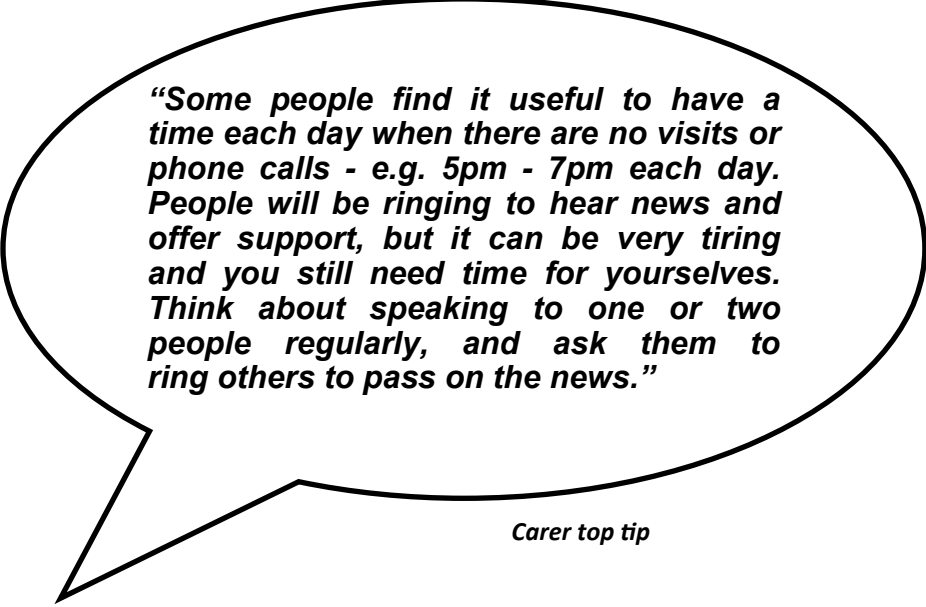
Specialist palliative care professionals do not replace your usual health care team but work with them. All have extra training, knowledge and expertise in providing palliative care.

Specialist care professionals may include:

- Palliative care nurse specialists (Often know as Macmillan nurses)
- Consultant Doctors in Palliative Medicine
- Psychologists

6. Support for you as a carer

As a carer you can be so busy looking after someone that you probably don't stop to think about your own needs. Your caring situation may also affect/ impact other members of your family, including young people.



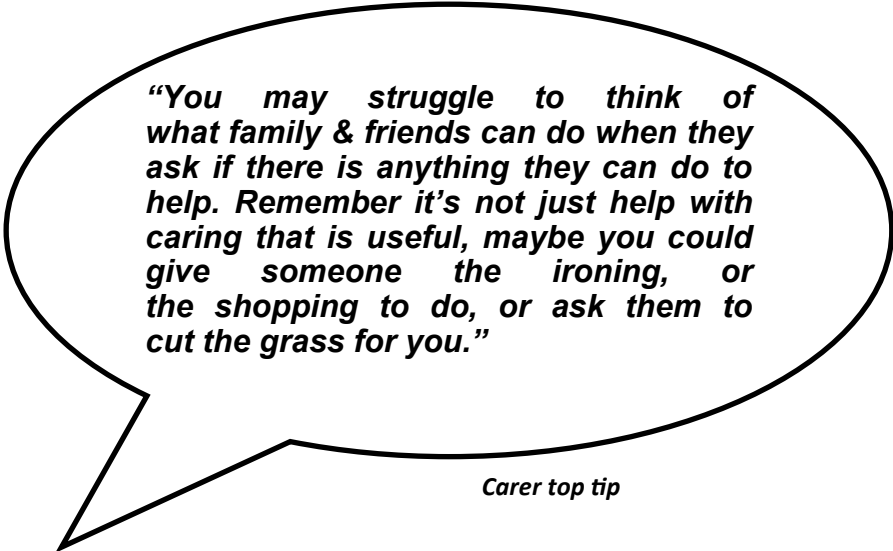
“Some people find it useful to have a time each day when there are no visits or phone calls - e.g. 5pm - 7pm each day. People will be ringing to hear news and offer support, but it can be very tiring and you still need time for yourselves. Think about speaking to one or two people regularly, and ask them to ring others to pass on the news.”

Carer top tip

Many carers face emotional and financial difficulties. Taking on a caring role can lead to feelings of isolation, frustration or depression so getting the right information, advice and support as quickly as possible can really help you to manage.

It might be helpful for you to think about:

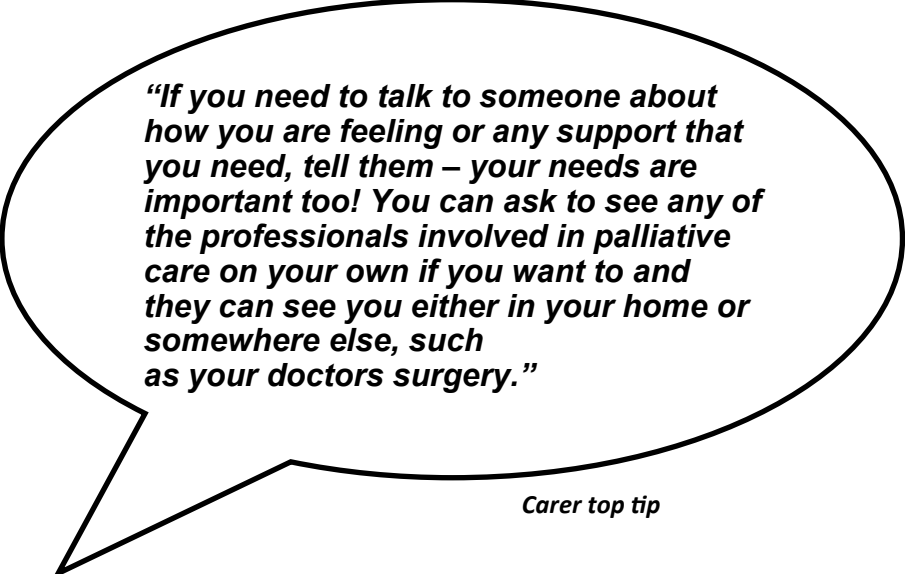
- How much time do you spend caring and what else do you do for the person you are caring for?
- Do you have any or enough support?
- Can you have a break and time for yourself?
- Is caring affecting your health?
- Your feelings – how do you feel about caring?
- What will happen in an emergency?
- Do you have contact telephone numbers for your GP and the community nursing service?
- What about your work, study, leisure time?
- Housing – do you have any difficulties with where you live?
- Do you worry about your housing in the future?
- Where can you talk about yourself as a Carer and get support?



“You may struggle to think of what family & friends can do when they ask if there is anything they can do to help. Remember it’s not just help with caring that is useful, maybe you could give someone the ironing, or the shopping to do, or ask them to cut the grass for you.”

Carer top tip

If you do need some additional support, you should speak to your family Doctor (GP), hospital Doctor, Community or hospital nurse who may be able to support you or make a referral to carer specific support services.



“If you need to talk to someone about how you are feeling or any support that you need, tell them – your needs are important too! You can ask to see any of the professionals involved in palliative care on your own if you want to and they can see you either in your home or somewhere else, such as your doctors surgery.”

Carer top tip

You can also contact Newcastle Carers who will be able to give you specific, tailor made advice, information and support for you in your caring role.

7. Planning for your future care

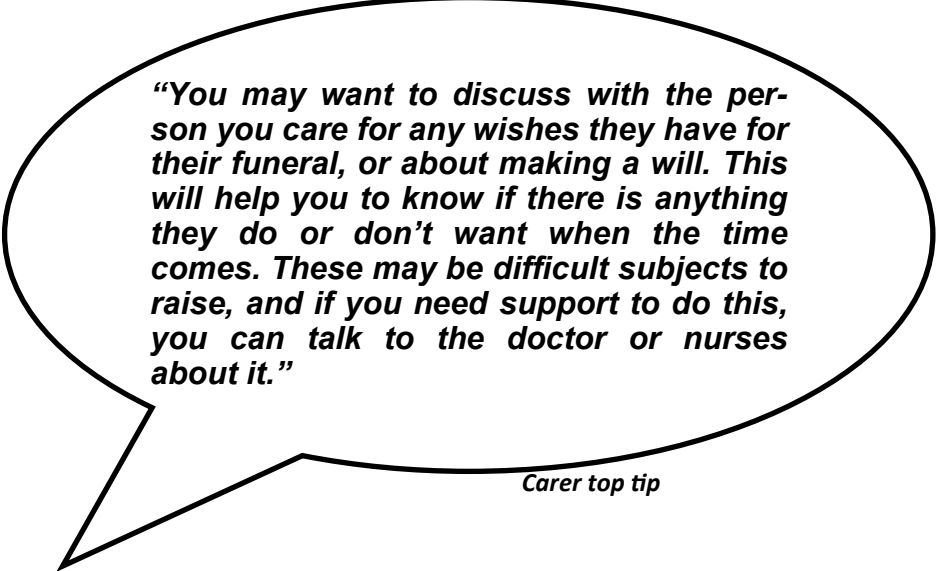
An important part of supporting people at the end of their life is to discuss their wishes and preferences for future care. Discussions could include practical arrangements when nearing the end of their life.

This is often called Advance care planning and is a process of discussion and review to help people who have a life limiting illness make decisions about their future care. It helps people to anticipate how their condition may affect them in the future, and if they wish, to put on record choices or decisions about treatments and their preferences about their place of care and where they might want to die. These can then be shared with their families, loved ones and with professionals responsible for their care or treatment.

The person you are caring for can choose if they wish to have these conversations at a time which is right for them.

The regional Deciding Right guidance supports people with information about planning for future care.

<http://www.northerncanceralliance.nhs.uk/deciding-right>



“You may want to discuss with the person you care for any wishes they have for their funeral, or about making a will. This will help you to know if there is anything they do or don’t want when the time comes. These may be difficult subjects to raise, and if you need support to do this, you can talk to the doctor or nurses about it.”

Carer top tip

You as a carer may, if you feel it is right, wish to talk to the person you are caring for about their wishes and future care thoughts.

This conversation may include:

- Where they wish to be cared for during their illness and when dying
- Putting their affairs in order and making a will
- Arranging and paying for their funeral

As a carer you may need to think about how you might feel and how your life will change when the person you are caring for approaches the end of their life or dies, this may include things like:

- Your home – will you still be able to live there?
- Your finances, their finances & any joint finances – get advice: don’t assume you will be able to use accounts & finances, even those in joint names
- Who will support you? for example friends, neighbours
- Work

8. What happens after someone dies

How you may feel:

Everyone's reaction following the death of someone you care for is different and a very individual experience which may be influenced by your culture and experiences. For some carers this also means a big change in their day to day routine.

Bereavement can cause unexpected feelings such as disbelief, anger, guilt, panic, relief or peace which may lead to tiredness and other physical symptoms. It is important for you to be able to grieve in your own way and not be told by others how you should be feeling or reacting. Children also grieve and may need support from you or appropriate professionals.

If you do need some bereavement support, you should speak to your GP who can put you in touch with organisations or services that can help.

Grieving takes time. Though it may be difficult sometimes to believe, most people gradually begin to feel less raw and rebuild parts of their life again, though that life will be different.

9. Useful Sources of Information

You may find that some of the following organisations can provide useful information.

NHS Social care and support guide

<https://www.nhs.uk/conditions/social-care-and-support-guide>

Community Health and Social Care Direct Newcastle

This is the team to contact for more information about social care, support available and needs assessments. Contact them to:

- find out about care and support for adults and carers in Newcastle
- ask for an assessment of your needs
- find out about local services and online resources
- get information in a language or format that meets your needs
- be referred into a service report abuse or neglect

National Organisations for Carers

Carers UK

www.carersuk.org

Tel: 0808 808 7777

Email: info@carersuk.org

Citizens Advice Bureau
www.citizensadvice.org.uk
Tel: 0800 144 8848

Alzheimers Society
www.alzheimers.org.uk
Tel: 0330 333 0804
Helpline: 0333 150 3456
Email: enquiries@alzheimers.org.uk

Multiple Sclerosis Society
www.mssociety.org.uk
Tel: 0300 500 8084
Supportcare@mssociety.org.uk

COPD British Lung
Foundation
www.blf.org.uk
Tel: 03000 030 555

Macmillan Cancer
Support
www.macmillan.org.uk
Tel: 0300 1000 200
Helpline: 0808 808 00 00

Parkinson's UK
www.parkinsons.org.uk
Tel: 0800 138 6593
Helpline: 0808 800 0303
hello@parkinsons.org.uk

Heart Foundation
<http://www.bhf.org.uk>
Tel: 0300 330 3322
Medical information and
support Tel: 0300 330
3311

The Neurological Alliance -
Neurological conditions
www.neural.org.uk
Tel: 01923 882 590
Email:
admin@neural.org.uk

The Stroke Association
www.stroke.org.uk/
Tel: 0300 3300 740
Helpline: 0303 303 3100
Email: info@stroke.org.uk

Huntington's Disease
Association
www.hda.org.uk
Tel: 0151 331 5444
Email: infor@hda.org.uk

Motor Neurone Disease
Association
www.mndassociation.org
Tel: 0808 802 6262
Email:
mndconnect@mndassociation.org

Newcastle Carers

135-139 Shields Road
Byker

Newcastle upon Tyne

NE6 1DN

Tel: 0191 275 5060

Email: info@newcastlecarers.org.uk

SMS: 0787 410 0043

www.newcastlecarers.org.uk

North Tyneside Carers Centre

Suite 9, Saville Exchange

Howard Street

North Shields

NE30 1SE

Tel: 0191 643 2298

Email: enquiries@ntcarers.co.uk

www.northtynesidecarers.org.uk

Gateshead Carers

John Haswell House

8-9 Gladstone Terrace

Gateshead

NE8 4DY

Tel: 0191 490 0121

Email: enquiries@gatesheadcarers.com

www.gatesheadcarers.com

Carers Northumberland

107 & 109 Station Road

Ashington

NE63 8RS

Tel: 01670 320 025

info@carersnorthumberland.org.uk

www.carersnorthumberland.org.uk

Notes:

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