

Caring for Someone Who is Terminally Ill

This section contains information on:-

**How You Can Help
Understanding the Illness/Treatment
Dealing with Symptoms**

Learning that someone you care for has a terminal illness

Caring for Someone who is Terminally Ill

Each person has different feelings and experiences. Some common reactions are:

- shock and disbelief;
- denial;
- anger and grief;
- fear.

These initial reactions may later be followed by feelings of depression and isolation.

Caring for someone who is dying is not an easy task. They may be experiencing anger, resentment, depression and withdrawal and often you may feel the brunt of these feelings.

How Can You Help

Practical Tips:

- accept the feelings of the person you care for;
- be prepared to cover the same ground on many occasions;
- be prepared for large changes in mood and outlook;
- simply listening is often offering useful support;
- if you are unable to cope with talking about feelings perhaps a friend, neighbour, relative or nurse may be appropriate;
- let the person you care for make decisions, try not to rush in and take over;
- being there is probably more important than doing things;
- get more information.

Understanding the Illness

As you begin to adjust to the news that the person you care for has a terminal illness, there are probably many questions you would like to ask, some of which are difficult to answer, such as:

- can you be sure that the illness is terminal?
- what are the options?
- what treatment is available?
- how will the illness develop?
- will they have any pain?
- will they need to go into hospital?
- will they eventually need extra help at home?
- how long have they got to live?

You can begin by asking your doctor these questions.

Asking Professionals for Information

You may meet a number of professionals during the illness of the person you care for. It is often difficult to remember all the questions you want to ask when speaking or meeting professionals. Here are a few ideas.

Practical Tips:

- be as clear and straightforward as you can about what you want.
- make a list of the questions you want to ask.
- let the person know how soon and for how long you think you will need to talk to them.
- don't be afraid to ask questions that might sound silly, those are the questions you need to know the answers to.
- consider if a phone conversation will be as good as an appointment.

- be prepared to see another person's point of view.
- make sure you understand what is being said.
- professionals, often without realising, use jargon - so don't be afraid to ask them to explain. If you don't understand, be persistent - keep asking.

Treatment

It is likely you will want to know more about a possible medical treatment. Try to use the practical tips above to find out what you want to know. Here are some possible relevant questions.

- what is the suggested treatment?
- what is the aim of the treatment? (e.g. is it intended to cure the illness, help the person you care for live longer or deal with their symptoms).
- what are the benefits of accepting treatment?
- are there likely to be any side effects?
- will treatment require a stay in hospital?
- if the treatment is planned on an outpatient basis, how long will each session take and how many will be needed and how do you get there and back?
- are there any alternatives to the suggested treatment?
- what will happen if the treatment does not take place?

In most cases there is time to think over what you have been told, so ask for time to consider.

Dealing with Symptoms

Symptoms will vary according to the illness and the same illness may affect people differently. Many symptoms can be reduced or relieved so tell your doctor or another professional about them. Do not assume its part of the illness and that nothing can be done.

Section 5 - Contacts

Cancer BACUP

3 Bath Place
Rivington Street
London EC2A 3JR

☎ (0207) 696 9003 (*please also see Pembrokeshire Cancer support group*)

Hospice Information

Information about home nursing and respite care for people with cancer or terminal illness.

Hospice House
34-44 Britannia Street
London WCI 9JG

☎ (0870) 903 3903
E mail: info@hospiceinformation.info

Macmillan Cancer Relief

Patient Welfare Dept
89 Albert Embankment
London SE1 7UQ

☎ (0207) 840 7840

Macmillan Nurses

The Macmillan Nurses and Clinical Nurse Specialist in Palliative Care offer advice, guidance, support, and supervision in relation to the care of individual patients and their carers/family. The Clinical Service Manager/Nurse Advisor (Cancer and Palliative Care) manages the 3 Clinical Nurse Specialists. Two are based in the community, and one is based at Withybush General Hospital.

☎ 0808 808 2020

Community Macmillan Nurse (North)
Winch Lane Medical Centre
Haverfordwest

☎ (01437) 774296

Community Macmillan Nurse (South)
Tenby Cottage Hospital
Tenby

☎ (01834) 843111

Macmillan Nurse
Clinical Nurse Specialist
Palliative Care Ward 10
Withybush General Hospital
Haverfordwest SA61 2PZ

☎ (01437) 773019

Parent line

For parents under stress

☎ 0808 800 2222

website: www.parentlineplus.org.uk

Paul Sartori Foundation/Hospice Care

The foundation is a lead specialist provider of palliative care in Pembrokeshire.

Nurses Team
31 Haven Road
Haverfordwest SA61 1DU

☎ (01437) 763223

Fax: (01437) 765755

E-mail: enquiries@paulsartori.wales.org

Pembrokeshire Cancer Support Group

Support to people who have or have had cancer, their families and friends. Providing a listening ear, emotional help and advice, enabling the person to fight their cancer and get through any treatment to be given.

The Duty Support Worker

Wesley Old Manse

Victoria Road

Pembroke Dock

☎ (01646) 683078

Hours: 9.00am to 4.30pm, Monday to Friday

Answerphone at all other times

Referrals: Accepted from all sources