



A Time to Care

Caring for someone
seriously ill at home



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We would like to thank the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet. We especially thank the families who generously shared their personal experience of the Night Nursing Service throughout this booklet.

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Reading this booklet

This booklet talks about the practical aspects of caring for someone who is seriously ill. It explains how to give the care that is needed and makes you aware of the resources in the community that are available to you as a carer. It also explains how you can look after your own health too. Contact numbers and details of local services are given at the back of the booklet.

Introduction

The aim of this booklet is to help you if you want to care for a seriously ill family member or friend at home. It is not unusual for those who are very ill to want to be cared for in their own homes. The Irish Cancer Society recognises this need and can help families in these circumstances.

Caring for someone seriously ill at home may be a daunting prospect at first. But with the right help and support it can be done. Often family members and friends can find it a very rewarding experience. You may also find that caring for someone in this way can help strengthen relationships.

Planning and preparation

However, looking after someone who is seriously ill at home can be challenging. Sometimes it can cause a lot of anxiety as people do not know what to expect. Depending on how ill the person is, it may involve 24-hour care and be too much for one person to take on. For that reason getting help from others and sharing the work is important. Before your relative or friend is discharged from hospital, planning and preparation is needed to make the change from hospital to home as easy as possible.

Looking after yourself

As a carer it is very important to look after yourself and be aware of your own needs and emotions. Be open to all offers of help and get as much support as you can during this time.

Who can help you?

Making the decision to care for a seriously ill relative or friend at home is not easy. At first you may feel overwhelmed or nervous at the amount of care they will need. Or you may feel that you don't have enough physical or emotional strength to deal with it all. Even so, you may still wish to make your relative or friend as comfortable as possible in familiar surroundings.

If you decide to care for your relative or friend at home, there are many healthcare professionals who can give you practical help and support. Some work in the community and some are attached to hospitals or hospices, while others work between the hospital and your home. Depending on where you live, services can vary from one Health Service Executive (HSE) area to another.

What is palliative care?

You may hear the words 'palliative care' mentioned. This type of care aims to improve the quality of life of patients and their families facing the difficulties of a life-threatening illness. As well as providing relief from pain and other symptoms, palliative care offers support and comfort to patients and involves caring for physical, emotional and spiritual needs in the best way possible. Your GP or public health nurse can tell you what specialist palliative care services are available locally.

The following is a list of healthcare professionals who will help you give the best possible care to your loved one. It does not matter if your relative or friend is based at home, in a nursing home, general hospital or hospice. Usually these professionals work as part of a team looking after your relative or friend.

General practitioner (Family doctor)

Your family doctor or general practitioner (GP) is an important part of the team that will take care of your relative or friend. The GP is medically responsible for their care at home. They work with the public health nurse and others involved in the care of your relative or friend. They can also refer your relative or friend to the specialist palliative care service. For more information on the specialist palliative care service, see page 8.

Public health nurse or registered general nurse

The public health nurse (PHN) and registered general nurse (RGN) in the community work with the GP and other professionals in the community. They will help in the care of your relative or friend. The PHN and RGN will make an assessment of your relative or friend as soon as they are informed by the hospital, GP or yourself.

After their assessment, the PHN or RGN will discuss what other services your friend or relative needs. They may ask other professionals or services to be involved in their care. That way you do not have to worry about contacting lots of people yourself. These services can include those of an occupational therapist, speech therapist or physiotherapist.

After the visit of the PHN or RGN, they will discuss what kind of equipment can help to make your relative or friend more comfortable. Or indeed anything that can help to improve their quality of life. They will guide you on how to get this equipment.

Care attendant (carer)

Care attendants may be available to come to your home and help with washing and dressing your relative or friend. The public health nurse will let you know if this service is available to you.

Home help

In general home helps provide help with things like housework, shopping and cooking. They may also give you a break by staying with your relative or friend if you want to go out for a short while. The public health nurse will let you know if this service is available to you.

Specialist palliative care service

The specialist palliative care service is also known as the 'homecare team' or the 'hospice homecare team'. This team gives advice and support to patients and families in the community. They are specially trained in managing pain and other symptoms and helping you cope with any emotional distress. The team is made up of doctors, nurses and other healthcare professionals. It may include a medical social worker, a physiotherapist, occupational therapist, and those who provide complementary therapies and pastoral care.

Palliative care in your area

Every county in Ireland has specialist palliative care nurses available to visit patients at home. For more information on other palliative care services in your county, the Irish Hospice Foundation has a directory of local hospice services available at www.hospicefoundation.ie/supporting/wayswesupport

Your relative or friend will be referred to the specialist palliative care service (homecare team) by their GP or hospital consultant. Once they are referred, the specialist nurse will arrange a visit. The specialist nurse will work with your relative or friend to see how best to help them cope with their illness. But they will also work with you and your family. They will explain who else is on the team and how they will be able to help you and your relative or friend.

The specialist palliative care service (homecare team) does not take over the care of your relative or friend but works very closely with their GP, public health nurse and any other healthcare professional or service already involved in their care. They can also refer your relative or friend to the Irish Cancer Society's Night Nursing Service when the time is right. For more information, see page 12.

Clinical nurse specialist in palliative care

The clinical nurse specialist in palliative care (homecare nurse) is a member of the specialist palliative care team and may work in the community, in the hospital or in both. When visiting you at home, they will work closely with the GP and public health nurse to give support to your relative or friend. If your relative or friend is having any difficulties due to their illness, they can receive help and advice from the specialist nurse. These nurses can also visit patients in hospital or in nursing homes.

Specialist palliative care service in the hospital

A specialist palliative care service is available in most general hospitals. This service works with the hospital team to give advice and support. A referral to the specialist palliative care team in the hospital is made by the hospital consultant.

Specialist palliative care inpatient unit

A specialist palliative care inpatient unit may be available in your area. Admission to this type of unit (hospice) may be suggested by the doctor in charge of your relative's or friend's care. You can discuss this in more detail with your specialist palliative care team.

Specialist palliative day care centre/day hospice

A specialist palliative day care centre or day hospice may be available in your area. Your specialist palliative care nurse can give you more information about this service.

Community pharmacist

The community pharmacist will make sure that all the medication ordered on the doctor's prescription, or bought over the counter, is correctly and safely supplied to you. They will also make sure that any new treatment prescribed for your relative or friend is safe to take with other medications.

They can also give information and advice on how and when the medications should be taken and on any common side-effects to expect. If you need more supplies, they can arrange this for you too. If there are any problems, they can discuss them with your GP and other healthcare professionals.

Physiotherapist

The physiotherapist can help your relative or friend with any mobility problems. They can also help with symptoms such as pain or excess fluid in the tissues or lungs. At home, they can teach you or family members how to move someone gently and position them in bed or in a chair. This is important because it will reduce pressure on sensitive areas.

Occupational therapist

The occupational therapist can make suggestions about any equipment or home adjustments that can make your relative or friend more comfortable. They can also help to make your relative or friend as independent as possible, for as long as possible. This is done by making sure they can do everyday tasks like bathing and dressing, eating and drinking, working (if possible), and are able to enjoy any leisure activities.

Medical social worker

If you are finding it hard to cope with caring for your relative or friend at home, the medical social worker can offer emotional support and help. They can also help children to cope with having a sick person in the home.

Caring for a relative or friend at home can be difficult, especially where finances are concerned. Your relative or friend may have been the main breadwinner before becoming ill, or you may have decided to give up your own job and work part-time. As a result, money may be tight, especially if you have extra expenses such as heating, laundry, special equipment or special diets.

The medical social worker can tell you about financial supports and community services. Some benefits are means tested but not all. You may be entitled to a Carer's Allowance or a Carer's Benefit, which may help with the extra expenses. If you are getting into debt or in debt, the Money Advice and Budgeting Service (MABS) can offer help. Call the MABS Helpline 0761 07 2000 for information.

Irish Cancer Society Night Nursing Service

The Irish Cancer Society offers 80 hours of nursing care to patients with cancer who wish to remain at home and be cared for by their families and friends. These hours are usually at night but in certain circumstances can be during the day. Your night nurse will work with you to give your loved one the highest standard of nursing care and ensure their comfort and dignity. They can also give practical and emotional support and reassurance to your family.

Access to the service is through either your specialist palliative care nurse, your public health nurse or your GP, who then contacts the Irish Cancer Society.

- We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.

Carer's organisations and support groups

There are a number of voluntary organisations in the country that may provide help and support for you as a carer and your relative or friend. In your situation they can offer practical support and give advice. Your GP, public health nurse or specialist palliative care service can inform you of local groups. See pages 42 and 43 for more details.

Preparations before going home

Once you decide to care for a seriously ill relative or friend at home, it is important that you understand exactly what is involved. Being a carer may mean helping your relative or friend with mobility, bathing and dressing, going to the toilet, giving meals and giving medication. Do make sure to ask the nurses for advice with any of these tasks.

Before the person you are caring for is discharged from hospital, sit down with the hospital staff and plan what you need in advance. Involve your relative or friend, if possible, because they should have a say in the matter as well. This means finding out information about:

- **Medication** – how often they must be taken
- **Diet** – any special food or drink that must be taken
- **Mobility** – advice about lifting or moving
- **Practical arrangements** – location of the bedroom
- **Aids and equipment** – special beds, mattresses
- **Nursing services available to you at home** – the public health nurse.

The hospital team will contact your GP and public health nurse to involve them in your relative's or friend's discharge from hospital. The team will update them on their condition and the care that will be needed. But it would help if you contacted both your GP and public health nurse too before your relative or friend comes home. The public health nurse can also give you practical advice. They can talk to you about any preparations to be done in the house, or if there is any useful equipment they can provide, such as a commode or a special mattress.

Medication

Ask for the prescription the day before discharge. Bring it to your local pharmacy to make sure they have all the medication in stock. Do ask one of the nurses on the ward to go through the prescription with you so that you understand about the medication before going home.

Practical arrangements

Bathroom

One important thing to consider is access to the bathroom.

- Is the bedroom too far from the bathroom?
- Does getting there involve great effort on the part of your relative or friend?
- Are they likely to wet or soil themselves on the way?
- Do they have access to a commode or urinal?

If the person you're caring for is incontinent, you will need to discuss this with your public health nurse before discharge from hospital. They can give you information and advice on how best to deal with the situation.

Stairs and bed

Is there a stairs in the house? Will the person you're caring for be able to manage the stairs? If not, discuss this with them as you may need to consider a bed downstairs. If possible, make room around the bed so that there is easy access to help them when moving position or getting in and out of bed.

If your relative or friend is upstairs, a baby monitor may be useful in the room, particularly at night. This means you can still hear them when you are downstairs or in another room. If you don't have access to a baby monitor, a bell can be useful so they can call you if needed.

Sharing responsibility

If you have a large family, it can be useful to plan a roster so that everyone is not there at the same time. That way everyone gets rest time and everyone is included in caring for your relative or friend.

- ● ● It was my closest friend's deepest wish to be able to die at the home she had lived in for the past 61 years. Thankfully, between us all, we helped her to do so.

Aids and equipment

Various items of equipment may be available to help you care for your relative or friend at home. The public health nurse or occupational therapist (where available) can advise you on what equipment is available, how to get it and how to use it.

Beds

It is important that your relative or friend is comfortable in bed. A lot of time may be spent in bed, even if they are not fully bed-bound. The public health nurse or occupational therapist will help arrange the most suitable bed and mattress for your relative or friend. Also, the public health nurse will give advice on the best way to make them comfortable in bed. It also helps to have a good supply of pillows at home.

Commodes, bedpans and urinals

If your relative or friend has difficulty getting to the toilet, they may need a commode, bedpan or urinal. The public health nurse or occupational therapist can arrange getting a commode for you. It is also possible to buy a urinal at your local pharmacy.

Wheelchairs and walking aids

Depending on their condition, your relative or friend may have difficulty walking. If so, the public health nurse or physiotherapist can arrange a wheelchair or a suitable walking frame.

Personal care

Washing

Washing your relative or friend regularly is important for many reasons. Not only is it good for their personal hygiene and comfort but also for their morale. It is also a good way to check for early signs of skin redness and prevent infection. For those with an advanced illness it often takes longer for bruises, infections or wounds to heal.

Many people who are in bed for long periods may sweat, get sticky and become uncomfortable. Indeed some cancers too can make people sweat more. If your relative or friend cannot get out of bed or wash themselves, they will need to be given a bed bath. Discuss this with your public health nurse, who will offer advice and support. It may be possible to arrange for someone to come in each day to do it.

When you wash your relative or friend



- Be as gentle as you can.
- Rinse the soap off fully and dry the skin gently but thoroughly.
- Change the water in the bowl several times during the wash.
- Keep your relative or friend covered as you wash each part of their body. Only expose the parts that you are washing. This helps to keep your relative or friend warm but also maintains their dignity.
- Look for dry or red skin areas, particularly in the ears, back of the head, shoulder blades, elbows, spine, hips, heels and soles of the feet.
- Use an electric razor when shaving as it may be easier.

Moisturising and massage

Your relative or friend may find that their limbs and back ache because they are in bed all the time. It can be very soothing for them to have these areas gently massaged with a light moisturising cream. A member of the team caring for your relative or friend can give advice on suitable creams or products. You may also need advice on caring for any areas of the body that have been treated with radiotherapy.

Mouth care

Clean your relative's or friend's mouth or dentures gently every day or more often if needed. If their mouth is very sore, use a fine baby toothbrush instead. It is best to avoid mouthwashes or lemon and glycerol swabs as they can dry out the mouth even more and can cause stinging.

Thrush and mouth ulcers are common when someone is very ill. Thrush looks like white patches or spots on the tongue, gums or inside the cheek. Dentures can also become loose and cause mouth ulcers. If the mouth or tongue becomes very sore or coated, tell the visiting nurse or doctor, who can give you advice on what to do. If the lips are dry, use lip balm to moisten them.

Hair washing and grooming

Being in bed all the time may make it hard for your relative or friend to feel or look well. Washing their hair may make them feel much better. Often this may not be easy to do, if they are confined to bed. Discuss with the public health nurse how best to do this.

Encouraging your friend or relative to apply some make-up can boost morale too. Also, encouraging them to shave with an electric or hand razor can keep their spirits up. If your relative or friend is unable to do this by themselves, talk to the visiting nurse.

Nail care

If your relative's or friend's nails need to be trimmed, discuss this with the visiting nurse.

Mobility

It is important that the person you're caring for does not stay in the same position all the time. Encourage and help them to move and change their position, if possible. This will boost not only their physical comfort but also their morale. It is important to help them feel independent for as long as possible.

Make sure that the floor is cleared of all obstacles such as shoes, rugs or other items that may trip them up. If they need to use a commode or sit out on a chair, make sure it is placed close by or as near as possible to the bed.

If you're looking after someone who needs help getting in and out of the bed, you will need guidance on how to move and lift them safely. When moving someone, be as gentle and careful as you can. Make sure you first discuss with your visiting nurse the correct way to lift and move someone. You do not want to cause injury to yourself or to your relative or friend.

Pressure sores

When your relative or friend has to stay in bed or sit in a chair for long periods, they can become sore and numb at certain pressure points. Any bony part of the body can become sore if pressure on it is not relieved frequently. People who are very ill and very thin are most at risk of developing sores. These can be uncomfortable and can increase the risk of infection.

In the long run it is better to prevent pressure sores from developing at all. Discuss with your visiting nurse the most suitable way to relieve pressure. It can be done by using a special mattress or cushion for when your relative or friend is in bed or sitting out on a chair. If they are confined to bed, discuss with the nurse how often to change their position. If you notice any change in the texture of their skin, such as redness or blistering, tell the nurse.

Poor appetite

Often people who are very ill have a poor appetite or none at all. Or their tastes and likes may change from one day to the next. Sometimes they may have little or no energy to eat, have a sore or dry mouth or find swallowing difficult. If your relative or friend has recently received treatment for their illness, they may not want to eat because they are feeling sick. If this happens, talk to the visiting nurse or the GP.

Tips & Hints – Poor appetite



- Give small meals often to your relative or friend instead of set times of the day. Or give meals whenever they feel like eating.
- Make sure the food looks as attractive as possible. Small meals and snacks can also help to stop your relative or friend feeling sick.
- Try moist food as it is often easier to take. It will help to prevent a dry mouth too.
- Offer meals when your relative or friend is sitting upright in bed or in a chair, if possible.
- If they have difficulty taking solid food, try liquidised food or a nourishing drink instead. You can also discuss with the visiting nurse the range of nourishing drinks now available. Your GP can give you a prescription for these too.
- Give them a glass of crushed ice or a bowl of ice cream as it can be refreshing. It will help to keep their mouth moist too.
- Use a straw for drinking, especially if the mouth or tongue is sore.
- Use a baby's feeder cup so it is not an effort to sit up to drink.
- Don't feel upset if they eat very little of your carefully prepared meal.
- Talk to the visiting nurse if your relative or friend cannot take any food. Nausea or vomiting may prevent them from eating and drinking.

Toilet needs

Sometimes your relative or friend may be very weak. As a result, they may need help to go to the toilet or use a commode or urinal. In this case, you might have to consider the location of the bedroom and how far or near it is to the toilet. You may find this upsetting, which is a natural reaction. It can also be embarrassing having to talk about it with your relative or friend. In fact, it can be one of the most difficult aspects of caring. Even so, do talk to your visiting nurse if you would like more advice on this matter.

There are many things that can affect how often urine is passed and the bowels are opened. These can be changes in eating habits, loss of appetite, lack of mobility and some medication. Discuss with the visiting nurse any difficulties you are experiencing. It is important that you ask for advice early. If the person you are caring for has no problems eating, it is helpful to encourage extra drinks. You can also add more fruit and high-fibre foods to their diet.

Incontinence

At some stage of their illness, your relative or friend may lose some or all control of their bladder or bowels. If this happens:

- You may need to discuss with your relative or friend the possibility of moving bedrooms to be closer to the bathroom
- It can help to keep a commode or urinal near the bed at all times
- Always ask the visiting nurse for advice.

The visiting nurse can give you information about using incontinence wear and protective measures for the bed. This is to make sure that your relative or friend is dry and comfortable and the bed is clean. If this does not work out, the nurse may suggest a catheter. This is a tube placed in the bladder so that urine can be drained away into a special bag. Having a catheter is painless and bags and tubes can

easily be hidden by bedclothes. For men it is also possible to drain urine using a tube connected to a sheath that fits over the penis.

Incontinence and using commodes in the bedroom can also cause concerns over strong smells. There are many ways of dealing with this so do talk to the visiting nurse about it.

Sleep problems

Your relative or friend may find it hard to sleep at night. This can be due to pain, sleeping a lot during the day or being anxious and finding it hard to relax. If you are concerned that you will not hear them calling you at night, use a baby monitor. This can be very reassuring.

There are many ways to help them relax and fall asleep at night. For example, listening to music, reading, meditating or a warm drink in the late evening may help. Make sure the bedroom is quiet and not too hot or cold either. Discuss ongoing sleep problems with your GP or visiting nurse.

- The night nurse's soothing voice and soft tones calmed our emotions and we knew by her confident actions that she was totally in control at all times.

Pain or any distressing symptoms

Your relative or friend may experience pain or distressing symptoms. If this happens, please encourage them to discuss it with the visiting nurse or a member of the specialist palliative care team. It is important that they take their painkillers regularly or as prescribed. If their pain gets worse, talk to the GP or visiting nurse. Gentle massage is also a good way to relieve pain. It may be helpful to keep a record of when they are in pain and what helped to relieve it or not.

Emotional support

It is natural for people with cancer or a serious illness to feel sad, anxious or depressed at times. Indeed they may experience a range of emotions and sometimes get cross or irritable with you. It is possible too for your relative's or friend's feelings to change from day to day or even hour to hour. Remember their emotional well-being is just as important as their physical health. Some ways to help deal with their emotions and feelings can include listening and talking, touch or simply being with them.

When to listen and when to talk

When faced with the prospect of the death of a family member or friend, it brings a strange mixture of feelings. It can be hard to know what to say to your relative or friend because the future is so uncertain. You may be afraid of saying the wrong thing and want to protect them and keep them free from worry. As a result you might pretend that everything is fine and carry on as normal.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer and is available from the Irish Cancer Society. It is also helpful for anyone coping with a serious illness. Call the Nurseline on 1800 200 700 for a free copy.

Tips & Hints – Listening and talking

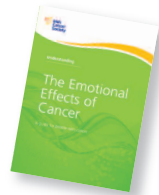


- **Listen carefully to what your relative or friend is saying.** You may think you are not doing much by just listening. But in fact it is one of the best ways to help. By listening carefully you allow them to share their feelings, which can help you to understand their concerns better. For example, they may be worried about finances such as wills or insurance. Or they may want to speak to someone to make amends.
- **Make sure your relative or friend knows they are not alone.** They may not want reassurance but just to be listened to as they talk about their fears and hopes. Even when there is no hope of recovery, they may want to know that they will not be abandoned and alone.
- **Be as honest as you can and be prepared to face the truth if that is what your relative or friend wants.** Often people who are dying do not want to focus on what is going to happen to them. But at the same time they want those around them to be honest. Sometimes they may speak about dying, or ask awkward questions such as 'Am I dying?' In this situation it's very hard to say an outright 'yes'. You may find it easier to respond by asking them a question instead. For example, 'Why did you ask that?' or 'Do you think you are dying?' This can give them an opportunity to express their worries.
- **Sometimes your relative or friend may not want to talk.** They just may not feel the need. But knowing that you are always ready to listen to them should reassure them.

Anxiety and depression

People with a serious illness can sometimes become anxious and depressed. However, it can be hard to tell if their symptoms are part of their illness or part of their anxiety or depression. They may lose interest in their surroundings, lose their appetite, be angry, irritable and cry, or have problems sleeping.

Deep emotional difficulties linked to a serious illness are not always easy to talk about, however. Often they can be hard to share with loved ones. If you feel that your relative's or friend's low moods are getting the better of them, discuss it with the visiting nurse or the GP. A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. It is also suitable for anyone coping with a serious illness. Call the Nurseline on 1800 200 700 if you would like a free copy.



Touch

Communicating with someone who is seriously ill does not always need to be verbal. As their condition becomes worse and their strength weaker, your friend or relative may speak less and less. Indeed you may find it hard to express your own thoughts and feelings to them. At this time, touch can be a good way to express your love and appreciation. By giving them a hug or holding their hand or by gentle stroking or massaging, it can help them to relax. Sometimes it may even relieve pain and sleeplessness. The fact that they can sense your presence too can also bring them great comfort and peace.

Peaceful environment

It helps to have a peaceful and soothing environment for your relative or friend when they are seriously ill and getting weaker. Music can be especially helpful and playing their favourite CDs or tapes can be very calming. If your relative or friend has pets, such as a cat or a dog, there is no need to exclude them from the room. A calm atmosphere should be encouraged and avoid crowding the room with family members and visitors. A room that has fresh or circulating air is also better than a hot stuffy one.

If your relative or friend has used complementary therapies in the past or is thinking about using them, talk to your visiting nurse or GP about how appropriate it is at this stage.

- ● ● While Mam wasn't awake to to meet some of the night nurses who cared for her, she would have been so pleased with the lovely way she was cared for and the respect her final days were given.

Spiritual care

When faced with a serious illness, your relative or friend may start thinking about the meaning and purpose of life, of God and the afterlife. They may have 'unfinished business' like spiritual or religious needs they did not get a chance to deal with during their lives. As a result, they may now want to address these needs.

In times of stress and sadness many people find that their religious faith can be a great comfort to them. Your relative or friend may ask to speak to a local priest, minister or religious leader for spiritual support. The illness of your loved one may affect your own spiritual well-being too. You too may wish to make contact with a religious leader.



Looking after yourself

Caring for someone who is seriously ill can be both a challenging and a rewarding experience. In practice carers provide all sorts of emotional and physical support. While it is true that caring for a loved one can bring great personal satisfaction, it can also be tiring, frustrating, distressing and isolating at times. Indeed you may become a carer overnight and feel that you are not experienced to handle the care of your relative or friend. And because their illness is unpredictable, you may be fearful or anxious about the future.

Caring for a loved one may result in you wanting to be at home all the time in case something happens. You may feel guilty about taking a break. Or depending on the support you are getting from others, you may have few opportunities to relax and take a break. Indeed you may feel angry or come to resent your loved one for the changes their illness has brought to your lifestyle.

However, do look after your own health too so that caring does not cause you to get stressed or sick. It may help to think about the following questions and, even if the answers are no, they can help you to focus on your needs too.

- Do I know someone who is a good listener?
- Can I trust them when talking about my feelings?
- Do I get enough rest and sleep?
- Do I eat regular meals and a healthy diet?
- Do I get some regular exercise?
- Have I got regular times for relaxation?
- Am I getting the financial support I'm entitled to?
- Am I allowing others to provide care and help too?

Family and friends

Remember to ask family and friends for help when you need it. Take up all offers of help, especially with finances, cooking, housework, childcare, shopping, or even company for yourself. Don't get weighed down by all your relative's or friend's needs. There are many healthcare professionals to help you if you find it hard to cope.

Talking to children

When caring for a relative or friend and there are young children involved, they may have many questions for you. In this situation, your medical social worker (if available), GP or visiting nurse can help you deal with these questions.

How much you tell children about the illness will depend on how old they are. Very young children do not understand illness and need a simple account as to why their parent or friend has to go to hospital or why he or she is ill at home and needs taking care of. Slightly older children will need to be told more.

An open, honest approach is usually the best way for all children. Even very young children can sense when something is wrong. So don't keep them in the dark – reassure them and talk to them in their own language.

A booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice on this matter. If you would like a copy, call the Nurseline on 1800 200 700.



Caring for your health

It is important to look after your own health too. It is best to take regular meals and exercise and especially to get fresh air. Exercise can also help you release any tensions that have built up. If you have any health concerns of your own, do not put them off but see your doctor sooner rather than later. Make sure to talk to your doctor about any concerns you have about caring for your relative or friend too. If you find yourself becoming anxious or depressed, discuss it with your GP.

- I want to share with you the wonderful presence and peace of mind that came with the night nurses, when your entire world is falling down around you. You want to be there for every waking moment but you realise that is impossible.

Time for yourself

It is best that you keep to some of your old routine and do things that give you a break. Stay in touch with your own friends and get out when you can – even if you do not feel like it. In fact your relative or friend may feel a little guilty that you are not getting out enough. Make time for a break each day: a walk to the shops, a trip to the hairdresser/barber, the library or cinema, or the odd evening out with friends. Give yourself little treats at home: read a favourite magazine or newspaper, sit down for a leisurely cup of tea or coffee, or have a relaxing soak in the bath.

Anticipatory grief

Grief is a normal response to loss. When a loved one dies, you grieve the loss of someone important to you. Many carers also experience anticipatory grief. This is the grief you feel when you are expecting a loss such as death.

Anticipatory grief can involve the same emotions often associated with grief, such as anger or denial. Anticipatory grief can also include feelings of depression, anxiety and deep concern for your loved one.

Like grief, anticipatory grief can also mean acceptance. Although this is a normal part of the grieving process, you may feel guilty about accepting the death. Remember that anticipatory grief can give you time to slowly get used to the death, and to say what you want to say or tell your loved one what they have meant in your life.

Not everyone experiences anticipatory grief before a loved one's death. Grief is a personal emotion and anticipatory grief is no different. This type of grief can also be different to the grief you experience when the person actually dies. The grief you experience before a death does not make the grief after the death last a shorter amount of time.

Tips & Hints – coping with anticipatory grief

- Recognise that anticipatory grief is a normal reaction to a loss that you know will occur.
- Do not feel guilty about anything you may be feeling.
- Talk about how you are feeling.

Practical matters

By knowing the wishes of your relative or friend, it can make dealing with a number of practical matters easier. To lessen any stress for you and your family when your relative or friend has died, it is a good idea to prepare a little beforehand. It does help to think about some practical issues that can affect your future.

Making a will

It is best to encourage your relative or friend to make a will, if they have not done so. Or at least to give them an opportunity to talk about it. Inheritance problems can often arise when no will is made. If you would like any advice about wills, dealing with solicitors or probate, contact the Citizens Information Phone Service on 0761 07 4000.

Important documents

It is also useful to know where important documents belonging to your relative or friend are located. This can include such things as the deeds of their house; their will; passport; driving licence; birth, marriage or divorce certificates (where applicable); details of bank or building society accounts; insurance and pension policies; and their personal public service (PPS) number.

If you need a night nurse...

At some stage when caring for a relative or friend at home, you may need the help of a night nurse. You can make a request for a night nurse through your specialist palliative care nurse, public health nurse or GP. They in turn will contact the Irish Cancer Society, who will arrange a night nurse for you. If one is available, the night nurse will ring you before setting out and introduce themselves. They will also tell you what time they will be arriving and will ask for directions to your home. The night shift is usually from 11pm to 7am but this may vary and can be discussed with whoever books the nurse on your behalf.

The night nurse does not usually wear a uniform but will carry an identification badge. They will give you an information leaflet about the night nursing service on arrival at your home.

About your night nurse...

- The night nurse is a guest in your home and is there to support you and not to take over. They will work with you and will provide whatever nursing care is needed for your relative or friend overnight. Any changes in their condition will be reported to the specialist palliative care nurse, the public health nurse or GP.
- The night nurse is there to offer you a chance to rest if that is what you wish. If you choose to rest, you should tell the night nurse who to wake during the night if they need assistance, or if there is a change in your relative's or friend's condition.
- The nurse will usually sit by their bedside throughout the night. However, it may be the case that your relative or friend is sharing a bed. In this situation you may prefer to ask the night nurse to sit outside the room and you can call them as needed.

What do I need to have ready for the night nurse?

There are a few things that you can do to prepare for the night nurse's arrival.

- It would be helpful to have a comfortable chair and a lamp or light in the room for the nurse and access to a kettle to make tea or coffee.
- The nurse brings their own food so there is no need for you to provide any meals or snacks.
- The nurse will also need to know where to wash their hands and where the bathroom is.
- If any written information or medication instructions have been left in your house, they should be made available to the nurse on arrival at your home. Any other equipment that has been left by the specialist palliative care team during the day should be brought to the nurse's attention.

- Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us. She is a very special person who does a difficult job with love and kindness.

When death is close...

When death approaches it is natural for it to be a sad and stressful time.

Dying at home may seem like the most peaceful, safest place but in practice this is not always possible for many reasons. Your GP or visiting nurse can offer advice and guidance in deciding the best place of care for your relative or friend at this time.

How do I know if my relative or friend is dying?

If you are caring for your relative or friend for some time, you may notice a change in their condition. The visiting nurse or GP will be able to answer any questions you have about this change and will advise you about any signs that your relative or friend is dying.

As the time draws near, their appetite will reduce or they may have difficulty swallowing. Offer small servings of a favourite food or drink but without forcing them. Do not worry if your relative or friend stops eating and drinking altogether.

Your relative or friend may sleep more and sometimes be drowsy or difficult to wake. So it is best to plan conversations for when they are more alert. They may also have difficulty seeing and may develop a fixed stare. In this case, it can help to leave a dim light on in the room. Sometimes they can become restless or confused. For example, they can pull at the bed linen and become confused about the time or may not recognise familiar faces. It is best to speak calmly so as not to frighten them. Remind them of the day, the time and who is in the room. It can be a comfort to them for you to hold their hand, even if they cannot respond.

When someone is drowsy or unresponsive don't assume that they cannot hear you. They may be aware of people close to them and recognise familiar voices. For this reason it's important not to discuss their illness or changing condition in their presence.

As your relative or friend becomes weaker, their breathing may change and become irregular. When breathing becomes shallower, secretions can build up at the back of the throat. These may sound noisy like a rattle. But it does not mean that your relative or friend is uncomfortable.

Time of death

It is very hard to predict when death will occur. If it looks like it's about to happen you may want to have someone with you. Continue to sit by your relative or friend and you will notice when they are no longer breathing.

When death occurs, you may wish to sit with your relative or friend for a while afterwards. Naturally you will have many emotions and feelings at this time. You may feel shocked or it may all seem unreal.

When a death at home is expected it is not necessary to call 999, the Gardaí or an ambulance service. In your own time, call their GP so that the death can be certified.

Practical help

After death occurs, you will probably need help to do tasks such as arranging the funeral and coping with visitors. Call the undertaker when you feel ready. They will help and guide you with all the aftercare of your relative or friend and the funeral arrangements.

Bereavement

When someone close to you has died, there is a natural period of sadness and loss. You are likely to experience a range of emotions from shock, relief, guilt to grief for a long time afterwards. These are all normal reactions. Some days you may feel better than other days. It is best not to try to do too much too soon. You will need time to get used to the loss of your relative or friend and adjust to a new routine. Wait until your grief is less strong before you make important decisions.

There are many organisations available to help you at this sad time. If you have concerns or find it hard to cope, contact your GP or your specialist palliative care service. A useful booklet called *Information for those Affected by Bereavement* is available from Citizens Information by calling 0761 07 4000.

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Patient travel and financial support services
- Daffodil Centres
- Night nursing
- Survivor Support
- Publications and website information
- Support in your area

Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email remote@slis.ie

Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 43 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Helpful books

The Irish Cancer Society has a wide range of information on different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website:

www.cancer.ie

You may find the following helpful:

- *Precious Times: A Handbook on Palliative Care for Parents of Children with Cancer*
- *Understanding the Emotional Effects of Cancer*
- *Understanding Cancer and Complementary Therapies*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Coping with Fatigue*
- *Diet and Cancer*



Useful organisations

Irish Hospice Foundation

Tel: 01 6793 188

Fax: 01 6730 040

Email: info@hospice-foundation.ie

Website: www.hospice-foundation.ie

Irish Association for Palliative Care (IAPC)

Tel: 01 873 4735

Email: info@palliativecare.ie

Website: www.iapc.ie

Website: www.palliativecare.ie

Care Alliance Ireland

Tel: 01 874 7776

Email: info@carealliance.ie

Website: www.carealliance.ie

Family Carers Ireland

Careline 1800 240 724

Email: info@familycarers.ie

Website: familycarers.ie

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Useful numbers

If you are caring for someone seriously ill at home, you may wish to write down the names and telephone numbers of people you might want to contact regularly or in an emergency.

NAME	TELEPHONE
Family doctor (GP)	
Specialist palliative care service	
Public health nurse	
Medical social worker	
Local pharmacy	
Other	

Would you like to help us?

All our services are funded by the public's generosity. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email fundraising@irishcancer.ie

Was this booklet helpful?

If you have any feedback to help us improve this booklet, please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on Freephone 1800 200 700.

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

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