

DYING AT **HOME**



Carers Notebook

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THE BENEFITS OF HOME

“There’s no place like home” – especially if you’re seriously ill.

70-80% of those recently surveyed in the West affirm this. The unfortunate fact is, however, that about 80% of people die in institutions.

The reasons for such an anomaly, flow out of our modern way of life and work, our busy-ness, the many demands on our time and energy. Add to this the noticeable lack of extended family in modern times. We no longer have multi-generation dwellings as we used to. And we no longer have a medical system that encourages home care.

Dying is not a medical illness requiring institutional, technological care. It is a natural event, part of living, to which, sadly, our modern society has largely developed a response of fear and denial. For generations this has meant a loss of a role model for this event.

In previous times the majority of people died at home.

The aim of **Dying At Home** is to respond to a dying person’s wish to be cared for at home by providing that person, and their Carer, with all the support, education, respite and back-up needed to make that possible, all brought into the dying person’s home.

We would say to the Carer or family, the two most significant aspects of the option you have chosen are:

- *Your loved one remains in control, in their own environment where they are most comfortable, most at ease, know and belong, and where, surrounded and embraced by family and friends, they may more fully live until they die.*
- *You will have the knowledge that you love this person in the most effective way possible, your loving care providing for such precious opportunities of intimacy at this time of greatest need, even to be able to grieve together as you travel with them along the way.*

It has been observed over many years that the dying person's physical and psychological care is much simpler and easier at home than it would be in an institution. Symptoms such as pain, for example, or nausea, breathing difficulties, confusion, sleeplessness etc. are often far less, requiring less medication. This is because their psychological state is enhanced by being in familiar surroundings in control and able to make decisions, have their choices. But especially so because there is less cause for fear and loneliness when surrounded by the love of family caring for you, and the familiar.

Apart from those benefits for you and your family, you will be providing for your friends and neighbours the opportunity for them to express their love and care, and a time of enrichment for them as they willingly share this journey with you. Moreover, children who may be fortunate enough to be part of this, will learn that dying and death are a part of living, not to be considered a frightening abnormality they would be better not to know about. They will witness its capacity for uniting people, bringing out the best in them, and fostering community.

“We all felt it was a challenge and a privilege to be with him right to the end and we have no guilty feeling at all about what may or may not have happened. We were there, holding his hand and talking to him to the very last moment.”

(Dorothy)

HOW DOES DYING AT HOME HELP?

DYING AT HOME CAN BE CONTACTED AT
WWW.DYINGATHOME.ORG OR INFO@DYINGATHOME.ORG

As the Primary Carer of someone dying at home you are involved in an enterprise that can be very costly, both physically and emotionally. You are obviously motivated by much love.

Dying At Home exists to enable you to maintain that care without the work becoming excessive and the task beyond you. Dying at home addresses the needs of the Carer, the dying loved one, and the Carer's personal community.

Whatever your needs in this situation, physical, emotional, social or spiritual, **Dying At Home** exists to provide for those needs so that you can happily do what you have set out to do. Despite the immense sadness it is essential that you not be exhausted by the enormous demands on your energies that make you unable to do this caring work happily. **Dying At Home** will ensure you don't get exhausted for want of support and respite.

The Programme has been developed over many years to assist people with a life-threatening illness, by providing sufficient support, education and back-up for the Carer so that the dying person could remain at home to die and not be taken away to hospital or hospice. It has the goal of providing those extra resources needed by a family, to remove the obstacles, correct some of the wrong ideas that deter people from this course, and to teach them and their friends the needs of the dying person (see THE GREEN BOOKLET and the FREE MEDICINES BOOKLET) and how to care for someone dying at home.

SPECIAL HELP FOR THE CARER – THE GATHERING

You cannot do this alone.

For the family caregiver, having a ‘GATHERING’ is the most helpful and essential part of the **Dying at Home** Program. It will enable you and your dying loved one to **live** each day together, surrounded by people who love and care for you. There are always people who want to support you. Be humble enough to allow them.

When other people learn you are doing something as difficult as caring for a dying person at home many, especially your friends, will offer to help you, “Let me know if there is anything I can do for you”.

That is what friends are.

You will need all sorts of help. And it is available.

It is important that your help is from your friends, and is your choice. First think: who among your friends or family is a “good organiser”? Someone whom you already know would be eager to support you in this endeavour. Ask that person to sit down with you and together follow the steps that lead to The Gathering.

1. Make a list of all those friends (and family) who you would choose to have involved in this work.
2. Make a list of all the ways you can think of in which you would need help, e.g., shopping, meals, washing/ironing, help with children, sitting with the sick person to relieve you, etc. Use the prepared list sheet below as a guide.
3. If you would prefer, ask your “good organiser” friend to invite those friends and neighbours on the list to a gathering to discuss the work you are proposing. (You may be surprised, those friends will consider the invitation a compliment.)

Friends at a time of crisis regard it as a rallying time for unity. The sooner they are invited to help, the better.

The Gathering

When your family and friends arrive your 'organiser friend' will explain why and how their help is so important at this time, both to you and to your dying loved one, and how grateful you are.

Your organiser will read the list of jobs, and call for a volunteer for each job. Record the name of the person who will do each job, and the day and date they can help.

What Help Does the Family Caregiver Need?

JOBS AND NEEDS	WHO CAN HELP	WHEN CAN THEY HELP	HOW CAN THEY HELP
COOKING/ MEALS			
MINDING CHILDREN			
GARDENING			
WASHING ironing			
SITTING WITH SICK			
SHOPPING			

Your organiser or another friend at the Gathering will watch over these helpers keeping them happily involved so that this help continues as the weeks go by.

Everyone involved in this work of love will feel good about being of help and will learn through the experience the value of what is being achieved. This privileged group of friends will become very closely bonded. Most important, they will be there also after the dying person has died as the best support for those who are grieving.

It is of the utmost importance that you, the Carer, have help - and that it is organised. The dying person will have a sense of relief to see you so supported. The alternative is stress and exhaustion for the Carer, and anxiety for the dying loved one.

This has been the way the program of Dying At Home has proved itself over many years in hundreds of situations. It is a win, win, exercise: for the dying person, the Carer and family, and the gathering of friends that represent the family's personal community. And it's free!

NOTES ON SELF CARE

These are the broad guidelines:

- Take it a day at a time, and LIVE each day.
- Take care of yourself – make full use of the ready help of your friends and neighbours. Pace yourself. Conserve your energy; you'll need it later when you won't want to leave the bedside. But while you can, take breaks regularly and relax. Give your loved one and your friends the chance to enjoy one another.
- Don't fuss about the unimportant things for now.
- Allow! Allow the family, especially the children, to help you. Allow friends to treat you, take you out, whatever. Don't make yourself indispensable, responsible for everything.

- Eat regular meals even if you don't feel hungry. Try to get enough sleep. Avoid becoming overtired. You might feel a bit irritable, worried and helpless. You might find yourself crying about the slightest problem. It is normal to have these feelings at this time of special demand on you and are indications that you need to have some rest and relaxation.
- Try to maintain a regular exercise programme, a daily walk or a turn on the exercise bike. Equally, make time for relaxation, yoga, Tai Chi or such, if you have been practising these things. Better still, if you and the family can do these things together.

SHARING EMOTIONS ALONG THE WAY

Many people have inherited inhibitions that prevent them from sharing their true feelings with one another.

This is no time for pretence. Rather it is a time for such intimacy and honesty, for openness with one another, carers, family and your dying loved one. Repressed emotions are very exhausting. Share your tears and you will be as free to share your laughter. And you will need both.

The great advantage of caring for your loved one at home is that you can truly be at home, sharing without constraints your emotions as you share everything else. Your doing so will allow others to do the same. Be assured this is what facilitates the grieving process, as it will your eventual healing.

“You understand what being human really means when you take care of someone who is dying.” (Chris)

TALKING ABOUT DYING

In some cultures, such is the fear, or the superstition, or confusion, people avoid talking about dying or death seriously. Even within families, members can be quite unaware what one another believes happens at the end of life. Apart from the fact that the body ceases to live, that it begins to disintegrate and so must be disposed of, we don't know. We have no knowledge of what becomes of that other aspect, the person. That is left to our beliefs. And we are often not prepared to share them.

That can create a problem when caring for someone dying. Not knowing what the dying person believes about death makes it difficult to console or reassure that person: what to say, what could be helpful, how the funeral is to be conducted, etc.

It would seem a good practice for trusted friends and family members at least to overcome their shyness on the subject and share their beliefs and hopes and aspirations. Just talk about it.

NOTES ON GRIEVING

The grieving begins with the awareness of impending loss, when you realise your loved one is soon to die. That is when the pain starts, the pain of coming to terms with the loss, becoming attuned to the reality.

That is why a family caring for a loved one at home can help one another by their living together at this time, and living as fully as possible – sharing, being sensitive to one another's pain, being patient and calm, communicating openly, avoiding overtiredness so as to remain in good humour.

Your loved one, of course, is grieving too and may need your help to find expression for that grief. It is more upsetting for him/her to have to hide feelings than express them. Allowing your loved one to cry – better still, crying together – is not to be seen as upsetting. That is the kind of intimate sharing both need at this time. It is a healing for the spirit.

You might need to find a trigger for this to happen. Reminiscing, looking at old photos, recalling the names of other loved ones are some ways to help the process.

This is not a time to waste on trivia, talking about things that are of no consequence, filling in gaps of silence with chatter. Your dying loved one will be listening to your words with much attention – as you are listening to theirs: what would you like to hear from them? That thought might help you realise there are things they would like to hear from you. What better time to tell them? Simply, honestly.

Why should we allow self-consciousness to inhibit expressions of love? Maybe you're not used to speaking to one another in intimate and endearing ways, and so you find it difficult. Why not say so? Tell your loved one about the difficulty you have expressing yourself. That may well be the problem your loved one has too, and this the only way the subject would ever come up. You're breaking the ice, giving them the permission to be daring enough to express what is in their hearts.

Remember this is a healing time, a time to bring people together before they are to be parted forever in this life. So if there is a need to talk about forgiveness, this is the time. You know it is limited and there may well be no other time than now. While ever your motive is a loving one, while ever kindness, gentleness and honesty guides you, you can only be doing something helpful.

This is one of the ways you will be doing your grieving along the way, and doing it together with your family and friends, and with your loved one too. And your grief experience following the loss of your loved one will be the better for it since you will have the knowledge of having shared so well, said what you wanted to say, heard what you needed to hear, helped with the healing of those you care for by your closeness.

In the months ahead and the years to follow you may want to have times and

rituals of remembrance. You and your family may want to mark anniversaries, birthdays, or other times that are of significance to you, with appropriate ceremony. Places, too, may help remind you and keep memories alive. Avoiding these things because they make you sad means more likely your sadness will not find expression, and your grief remains within you more heavily. Despite the pain you need to grieve.

However you deal with your grief, know that it will not be easy. Know that it is the most natural thing to be hurting, and unnatural not to be expressing the hurt. You will know that no-one will know how you feel.

Time and patience are required, but you will keep your hope alive if you remain calm and trust the natural process, flowing with it rather than resisting with pretence of strength.

SPIRITUALITY

In your loving care of this person who is dying you will be aware there is more here than a body. **The spirit of this person**, the mystery that tells you that within this ailing body is a living person who knows and loves and feels, with beliefs and hopes, calls you to extend your care beyond the mere physical, and beyond the mere emotional, to the very **dignity and destiny** of this person.

Some people's spiritual life has not necessarily involved them in any religious or cultural affiliation. For others their religious life has lapsed without their having lost their spiritual life, they may want some help to renew or deepen that connection with their religious or cultural traditions.

We can't assume that we know what a particular person's conscience may be on this matter, where they stand with their God or what they would like to do about it. Nor should we assume that it is of no consequence. It may not be to us, but our duty is to the one we're caring for. What does he/she want?

For the believer the consolations of religion are many. The non-believer may

not understand the reasons for this. But the non-believer's obligation is to serve the loved one, so it is that person's mind and will on this matter that is paramount.

Ever so gently and respectfully, without imposing our beliefs or practices on another, we let them know we understand they may have needs in this regard, and that we are there to do our best for them. What would they like us to do?

If they have indicated they would like a visit from their spiritual or cultural adviser arrange it so they have privacy and not be interrupted during that time.

If you and your loved one have shared your spiritual lives, prayed or worshipped together, then, quite naturally and without fuss or self-consciousness, spend some quiet time doing just that with them.

These times should not be long and tedious. Be sensitive to your loved one's needs and wants. They may have limited energies, so don't go on and on, exhausting them. Let them rest while you, perhaps, read something for them. Children in the home can have a special contribution to make in this aspect of your caring, and they themselves may benefit greatly from the involvement at this deep personal level, especially in their subsequent grieving. So, if it is appropriate, let them be with the dying person at such times.

This is surely one of the best advantages of being able to die at home. The privacy required to attend to things as personal as this is available in one's own home where you may be relaxed and unhurried and the dying person is spared any unnecessary embarrassment.

Know that, in the mind of your loved one, this could well be the most helpful thing you could be doing for them.

TAKING SOMEONE HOME FROM HOSPITAL – SETTING UP AT HOME

STEP BY STEP GUIDE

Ask (head of staff or person in authority) for a meeting with Specialist, GP and head staff and nursing staff and other specialists (eg physiotherapist, occupational therapist, oncologist) involved to have a case study of the patient.

Make it clear that you want to take the patient home to die.

Ask where the local Palliative Care team is located and their contact details.

Ask about policy and procedure of moving a patient (eg ambulance, 4 wheel drive).

Ask the Specialist or patient's doctor to write a referral to the local Palliative Care team so that the process required to bring Palliative Care to the patient can be started. This process can be started even when there is no definite date for taking the patient home.

Locate the **hospital discharge planner**. Ask for a meeting to discuss home modifications, home appliances, community services e.g., home help.

Make sure (probably by phone) that the **Palliative Care or Hospice Team** will be visiting as soon as possible to follow up. Palliative care teams can be made up of various health professionals. Meet with Palliative Care team to discuss equipment, home modifications, access to community services and home help, Palliative care teams visiting schedules and contact details, medications required for the loved one and how to administer them, demonstrations and education on specific techniques of care the family can do for their loved one (bathing, turning, changing clothes and bedding, moving, managing pain relief and other symptoms) financial and employment issues.

Talk to the specialist involved. Ask the nurses on the ward to arrange a meeting or ask your specialist's registrar to arrange one. If all else fails call the specialist's room and speak direct.

You need to ask all the questions you want answers to, so write a list of questions before you meet with the specialist.

Since you will be doing the caring from now on you will want to know what is happening in relation to the disease, the good news and the bad news e.g.,

- Possible symptoms which may develop, especially anything that might occur without warning
- Whether any further treatment is planned
- Whether there is to be follow up by specialist
- How best to deal with medical problems as they arise

Talk to your G.P.

- Ask if your G.P. is ready to visit your house on Day 1. Request this house call ahead of time.

- If she/he is going to be away at any stage, she/he will let you know of alternate cover for that period.

Make sure **medications** are carefully written out for you and the initial supply (usually 5-7 days) is provided by the hospital.

If the hospital **chaplain** has been visiting in hospital you may want chaplaincy follow up and provide the link to the support from your nearest church.

Do a big shop before you bring your loved one home.

If the hospital dietary department has been good, ask for **nutritional advice**.

Get an **answer phone** – so you don't have to answer the phone every time it rings.

Get an **Intercom** if your loved one is bed-bound. This frees you to do a bit of

gardening, take a swim in the pool or whatever you need for recreation, without fearing that you are unable to hear a call for help.

Rearrange the furniture if you need. Many people when bed-bound like their bed in the living room with the best outlook.

If there are **special care instructions**, like “ostomies” etc., meet the stomal therapist in hospital and make sure the discharge planner has linked you to the special nurse who will visit you in the home.

If you need **special equipment** or home modifications get this all set to go. (Your discharge planner or palliative care nurse should co-ordinate this).

Arrange a family meal a few days before taking your loved one home to share information with your family and get their support.

Have 2 or 3 dinners in the freezer ready to heat and serve. (Ask your neighbours or friends for this; then you have begun an important step of inviting their loving help).

If your loved one is very weak and ill when she/he is brought home, the amount of physical work you will suddenly be deluged with will surprise you – reminiscent of bringing the first baby home!

The aim in setting yourself up as well as possible, using also all available resources, is to provide you both with a time which is **rich in living** – time to read, watch movies together (especially funny ones), reminisce, enjoy family togetherness, take walks, drives, or just sit in the sun. There can be energy enough if you use all available resources and gather around you all those willing friends and neighbours to avoid being exhausted by the physical work.

CARERS' REASSURANCE GROUP contact dyingathome program at info@dyingathome.org to be put in touch with a volunteer from Carer's reassurance group.

This group of people is an added resource for Carers to make contact with to draw from their experience in caring for a loved one at home.

They are a group of people who came forward after the experience of caring for someone dying at home. They simply wanted to pass on to others something of what they had learned. They understand what is going on in your home, your fears and questions. They are able to speak to you having been through the experience.

Our community has all but lost the art of caring for the dying at home. But we can draw on the wisdom of those who have travelled this road themselves.

USEFUL EQUIPMENT THAT MAY BE AVAILABLE on loan, for rent or purchase

Absorbent pads for bedding

Air mattress

Bathroom safety equipment ...rails

Bed Side rail to pull up on or to protect from falling out

Boomerang pillow

Call device to ring pre determined phone numbers in an emergency.

These should include neighbours and family members' phone numbers and your personal community of supporters

Elevated toilet seats/commodes

Hoists/slings/lifters for moving in and out of bed and chairs

Hospital bed

Monkey bars,

Nebulizer/fans /humidifiers

Rubber gloves to prevent spread of infection

Sheep skins

Shower attachments

Shower seat or shower wheelchair
Spenko mattress cover, ideal for back, and joint pain, and bed sores.
Sterile pads and dressings
Swivel seats
Walking aids: walkers, canes, tripods
Water chair
Water cushions
Water proof bed sheeting (Kylie)
Wheelchairs

The sick person should be encouraged to be an active participant in home care and assume whatever level of independence she/he is capable of achieving. We all need to contribute, even if energy is limited.

SAFETY MEASURES IN THE HOME

Remove scatter rugs
Clear small objects from floors
Avoid loose and floppy shoes
Install railings wherever possible e.g. by Community Services
Install non-slip adhesive backed strips in shower or tub
Plug in night lights and movement sensor lights into power points
Keep a torch handy

COMMUNITY SERVICES THAT MAY BE AVAILABLE IN YOUR AREA

COMMONWEALTH RESPITE AND CARELINK CENTRE 1800 052 222 in Australia gives advice and access to services in the Carer's local area
Community nurses
Palliative Care Community Team / Hospice Programs
Home Help
Veterans Affairs for financial assistance, nursing in the home, home help, etc.
Social Worker for financial help, Carers pension, etc.
Neighbourhood aid
Meals on Wheels

Carer Respite Services and Organisations

Home Library Service (books delivered to your door every 2 weeks. Includes magazines, talking books, etc.)

Church “care groups”

Physiotherapy

Podiatry

Other Location Specific Services

NUTRITION, EXERCISE AND LIVING

You have brought your loved one home and set everything running in the home. The whole aim of being at home is to live as fully as possible together.

Have a friend drop by the DVD shop regularly to get DVDs for both of you to watch. Maybe try some games, cards or chess.

Have friends / family cook something nice and bring over to have a dinner party. This way it's no fuss for you.

Some people want to write legacy letters when they are thinking back over their life and events,

Some people just enjoy reminiscing with family over photo albums. This may need special encouragement.

A CD player at bedside allows for easy use of relaxation/meditation tapes interspersed with favourite music.

FOOD PREPARATION AND SUGGESTIONS ON WAYS TO TEMPT THE PATIENT TO EAT

When we are sick our appetite decreases. Physical weakness makes exercise difficult and our immobility leads to a further loss of appetite.

Overall, do what you can to tempt your loved one to eat, but you may have to forget about regular sized meals. Try offering six small meals a day.

Sustagen and similar products are very good for in-between snacks.

Try for one multivitamin tablet a day. That is all that is needed to keep pressure areas from developing and to promote wound healing.

Have friends cook small-portion meals and snacks. Stock the freezer.

Home made fruit ice blocks are great in summer.

Milkshakes with a dash of brandy are good for some.

Where your loved one just can't eat, don't fret. Just try again later; eating can no longer be forced. As long as sips of fluid are maintained there is no fear of discomfort from dehydration.

EXERCISE:

It is important for the whole family.

Your loved one discharged from hospital will feel surprisingly weak having been immobilised in bed for even a week or two. A return to strength doesn't just happen; it will have to be built up and regained gradually.

It may only be a matter of wiggling toes and twisting ankles, flexing and relaxing groups of muscles in bed. Do it three times a day for 5 to 10 minutes and you will see the strength beginning to return.

Breathing exercises to start with are great. Fill the lungs, get more oxygen. Some could take a walk once a day. Walking from bedroom to kitchen three times a day will extend rapidly to a walk into the yard. In summer walking to the pool, maybe dangling legs in the water, can be refreshing.

The thing about exercise is to make a start somewhere, and have a goal to encourage you. You will be surprised.

WHAT ABOUT THE CHILDREN?

Think of the decision to share the experience of caring for someone dying at home with the children as a special and rare gift to them. But it needs some careful thought. You will need to ensure sufficient time and attention to enable them to understand that this is simply another part of the life cycle, difficult and painful as it may be, but natural, and not to be feared.

Your emotions may not allow you to deal with their many questions. Just talk to them about the difficulty, and perhaps ask another family member or close friend to be their support person for the time being till you regain your equilibrium. It is vital for someone to allow that open forum.

Children can often do helpful things for the sick person. Let them show their care in simple ways, such as playing little games with the sick person, sitting with them while you are free to attend to other things. Nothing onerous or demanding. The loved one may be well enough to enjoy sharing family photo albums and videos with the children. It can be an enriching time, with as much laughter as tears.

For younger children who recognise this as a significant time, you could suggest a drawing book for them to record the events and feelings they may not have words to express. For older children perhaps a diary.

Tape recording talks OR videos with the family. Helping the dying person write messages, draw memoirs, is something all can be involved in.

The child may for good reason ask for a special outing. Try to find a way to be free, perhaps by arranging for a friend to sit with the sick person.

When the time comes that the dying person, especially if the parent, is close to death, let the children make their own decision on whether to stay home or go to school. Invite them to share as deeply in the experience as they wish.

After death has occurred be relaxed about allowing the children to physically experience the reality. It is important for them to make their own decision about touching, stroking and observing, taking as much time as they need.

Inviting children to be involved in the funeral ceremony is often very important for their grieving. Their involvement can add beautiful ritual to the ceremony.

NON-MEDICAL RELIEF OF SYMPTOMS

It is essential for those who are seriously ill to have well practised techniques of deep rhythmical breathing and **a regular relaxation exercise**. Many of the symptoms listed here such as pain, anxiety, restlessness, sleeplessness, nausea and breathlessness can be significantly relieved as long as these techniques are well practiced.

To practise relaxation, select a relaxation CD. For this to be really effective, do the exercise three times a day for just 15 minutes. For the one who is ill, it is so beneficial to become very practised at relaxation. For their Carer it is a wonderful self help technique to practise for self care. Then, when unsettled by pain, anxiety or breathlessness, this alone will be a profound support to relive such symptoms. And most important you will have some control. As a Carer you may want to do this together, as it is equally beneficial to you. This is invaluable for body and mind and spirit. Trust the process.

What follows in this section of your notes are suggestions on how you as Carer can assist your loved one and give relief across a wide range of problems. If symptoms are not relieved with these home remedies and techniques, always keep your doctor/community nurse/palliative care team involved and informed. Should it seem to be a serious problem, it is helpful to start using these suggestions straight away, until the nurse or doctor arrives.

Symptoms, and Suggestions on their Relief

ACHES

Often occur because of immobility.

Reposition.

A Heating Pad or hot water bottle is always a comfort.

Gentle massage and stretching of limbs.

Spa bath - if available.

ANXIETY

Breathing exercises - a simple one is 'purse lip breathing'. Breathe in through the nose and then out through the mouth as if going to whistle. Keep eyes closed.

Relaxation practice - use your CD to focus on this. As you become practised there is no need to keep playing the CD- it has become a part of you, to call on any time and anywhere.

Play soothing music.

Stroke sick person's forehead, or neck and shoulders and encourage 'purse lip breathing'.

When settled try to talk about the cause of the anxiety.

Sometimes a counsellor or minister of religion may be helpful once the episode has settled.

BEDBATH

Very soothing for a person who is bed bound.

Technique:

Put 2 litres of very hot water in a bucket, hot enough to last through the bath. Add to the bucket 30mls of baby wash, Alpha Keri dry skin wash, or similar non-soap based product, plus a few drops of lavender oil.

Have ready:

2 towels and 2 washers

1 towel to pat dry (preferably warmed e.g. in clothes dryer)

Place one towel in bucket of hot water, wring out one towel from bucket and place warm wet towel on front of person and leave on for a time, then pat dry

with warm dry towel. Turn over to the back (if comfortable on stomach) and do the same. If uncomfortable on stomach then do the back in a sitting position.

The washers are for face and hands. Offer to the sick person to do their own hands and face.

At the end of this part, place their hands in bowl of warm water.

BED SORES

Prevention

The very best prevention is to reposition regularly.

Sheepskin booties and under rug/or pillow for heels, and low back areas.

Keep skin dry in pressure areas, especially heels, lower back.

Massage gently with Baby Sorbolene or similar cream for circulation.

Take 1 multivite daily, as this can prevent skin breakdown and be very helpful if started early once someone is in bed a lot of the time. Should be routine for people who are sick and not moving around a great deal.

Care once sores are present

If this happens contact the community nurse as soon as any area of skin breakdown occurs. It is time for special dressings. Continue with the sheepskin and multivite tablet.

BREATHLESSNESS

It is vital to have a small fan available and start right away at onset of breathlessness. Have a small fan (hand-held or table fan) blowing air onto your loved one's face, and open the windows (even in winter). This is the most powerful tool for relieving breathlessness, often more relieving than oxygen. Of course if your loved one is already using oxygen, keep it in place and use the fan at the same time.

To explain: a fan blowing directly onto your face especially on the cheek

'tricks' the brain into thinking there is plenty of air getting to the lungs. The brain signals the lungs to relax and gives immediate comfort.

Other suggestions:

1. Sit upright in bed. Rest arms on tray or pillow on lap. This opens diaphragm more fully.
2. Use 'Purse Lip' breathing. Breathe in through nose, out through mouth as if going to whistle.
3. Talk your loved one through their relaxation exercise.
4. If one lung is diseased prop patient up and lie patient on that side. A rolled up towel will help keep them in position.

CONFUSION

Sit and talk in a calm way with the sick person.

Calmly say your name and that you are near to reassure loved one they not alone.

Touch is very calming.

Explain where they are, that they are safe.

Always explain what you are doing.

Keep your loved one part of the family, not separate.

Have a night light on at night.

Play soothing music.

CONSTIPATION

1. ESSENTIAL - plenty of water and other fluids every day. Remember, if sleeping a lot, to 'catch up' on fluids when awake.
2. Eat fresh fruits daily: e.g. choose from fresh apples, pears, red papaya (an excellent natural cure), bananas and dried prunes and figs. May be blended or pureed.
3. Pure juices, especially prune and pear juice.
4. A dessertspoon/tablespoon of bran on cereal, soups daily.

Note: Many drugs used in palliative care are constipating and the sick person

may still need medication, but often far less if the above is strictly adhered to.

COUGH

WET COUGH

Sounds moist.

It occurs because the patient is too weak to cough up mucous.

Chest physiotherapy is very effective.

Technique:

Sit upright, lean sick person forward and start to pat the back (not heavily) from the lower part upwards to the top of shoulder blades. (The target is the mucous in the chest).

If the patient is too weak to sit up, do one side then the other whilst lying down. Use a rolled up towel to prop the patient on their side. This moves the mucous and stops the cough.

Often just repositioning helps.

For a child use fingers and for adults use whole hand.

Do morning and night especially, so you can all sleep!

DRY COUGH

Needs soothing to stop.

If painful sit up and hug a pillow.

Warm pack or cloth to chest relieves tightness.

Cough syrup:

2 tablespoons of honey in a cup of warm water, sip slowly.

Lemon grass tea or a squeeze of lemon, add honey and sip it warm.

Eucalyptus and honey candies to suck.

Suck small pieces of ice.

DRY LIPS

Lip balm, Paw Paw cream, vaseline, sorbolene.

DRY MOUTH

Frequent sips of ice cold water or mineral water.

Suck ice blocks, pineapple chunks, cucumber, fruit.

Make iceblocks from pureed fruit.

Fruit-flavoured candy to suck on helps saliva flow.

Dry mouth spray is made very easily. Purchase a spray bottle from the pharmacy. Fill with water and keep close at hand use as often as desired. Very helpful.

Techniques to make the saliva flow

1. Using the sick person's imagination, suggest the image of a lemon. Suggest the image of the lemon being cut slowly, and the person sucking it. Now you will have saliva naturally in the mouth.
2. Place the palm of your hand firmly underneath your chin, hold it for a moment or two. When your chin is in the palm of your hand this presses on saliva glands and stimulates saliva flow.

Note: Don't forget to offer more fluid intake. A dry mouth is a good reminder.

DIARRHOEA

Beware! It may mean quite serious constipation with a sort of overflow state; if so, treat the constipation. See under constipation, also let your GP and community nurse know right away as it will need special medication to be added into the regime.

If true diarrhoea:

Increase fluids, salty broth, tea without milk, oral rehydration solution purchased from a pharmacy.

Cola drinks are especially good to stop diarrhoea, if tolerated.

Give plenty of boiled water as well.

Avoid:

Milk, dairy products such as yoghurt for a bit.

Cut back on fresh fruits, vegetables, cereals, spicy foods until normal.

If it is hot weather it is vital to take plenty of the safe fluids as above to prevent dehydration. Note that very sweet liquids like lemonade can worsen dehydration.

DEHYDRATION

Recognise the signs in children and adults.

Skin hot to touch, dry tongue, dry lips, thirsty, sleepy, movements slow, skin no longer elastic (gently pinch up a piece of skin on the forearm, see if it is slow to go back into place).

Children may look dark around eyes, are 'floppy' in their limbs and neck muscles.

Provide water, constant sips, shaved ice, broth, etc.

EARACHE

Wax build up is often the problem, in which case ear needs wax dissolving drops (purchase at pharmacy) and after 2-3 days can be washed out in the shower.

Sometimes pain in the ear comes from the jaw. Warm packs are comforting.

FEAR, PANIC ATTACKS

If caused by breathlessness see that section, but first get the hand held fan going straight away.

Always encourage deep slow breaths and help your loved one focus on air going 'in and out' of their lung. Say it over and over.

Touch for comfort and reassure that this will pass.
or hold their hand and quietly encourage deeper breathing.

Play soft soothing music in background.

When the patient is more relaxed allow plenty of time to just sit and talk about the real anxieties and distressing feelings below the surface.

If a child, hold close, sing gentle songs, hum, massage gently.

FEVER

Fan.

Sheet only to cover (even in winter).

Tepid sponge or use wet towels over face, stomach, back and limbs - **replace tepid sponge when sick person becomes too warm.**

Encourage fluids to make up the losses through sweating.

FLUID IN LEGS

Elevate feet on soft pillows whilst sleeping (above heart level) if not uncomfortable. This gets fluid out of the tissues and back into the circulation. Avoid sitting with legs hanging down. Always use a footstool as high as is comfortable. If a hard surface place a soft cushion under feet.

At the upper level of the swelling on the legs do a very gentle slow massage of legs upwards around the whole circumference of the leg, to return fluid to circulation. This done 3-4 times daily for several minutes and elevating the feet while sitting stops fluid accumulating through the day. Use cream or oil to avoid damaging fragile skin.

GROANING

This sound can be very disturbing to hear. It occurs when someone is close to death and often in a very deep sleep. It does not necessarily mean pain is present. It is caused by air passing over weak voice muscles that vibrate.

Talk softly to orient to the time of day and who is present. Its fine to ask questions, gently and one at a time. If you wait you often get clues that are answers in a different way from usual. There are people who call this coma communication.

Reassure and make sure they are not in an uncomfortable position. Often propping up on several pillows will decrease the sound.

Take time to ask them if they are in pain. Often a squeeze of the hand or eye movements will give you the answer. People are very communicative at this end of life time, but we need to learn their 'language' and it takes time and patience at the bedside.

HEADACHE

Neck or temple massage.

Deep, effortless, relaxing breaths.

Make sure head and neck are in a comfortable position on pillows especially through the night.

Increase water intake as dehydration can often be the cause of headaches.

HICCUPS

Sipping iced water.

Sit upright if lying flat in bed.

Valsalva manoeuvre (holding nose and swallowing three times).

Massage ear lobes at the same time and swallow several times.

Eat a teaspoonful of granulated sugar.

Biting on a lemon.

Breathing into a paper bag.

Note: Any of these techniques can stop hiccups. Sometimes you need to try several to find the best one.

INCONTINENCE

Change pads and clothing as soon as possible.

Wash and dry skin, apply zinc and castor oil cream to prevent sore skin.

Offer toileting after each meal.

Use plastic sheeting for bed, Blueys, Depends.

Ensure no contact of blood, urine or faeces if the carer has open wounds.

ITCH

Mildly warm or cool baths and showers.

Note: Although it seems that really hot water relieves the itch for a short while this actually worsens itch. The reason for this is that the hot water makes the cells under the skin causing the sensation of itch, to become more active.

Always wash with Aqueous Cream not soap (purchase at pharmacy).

Oatmeal baths are very soothing. Tie a handful of oatmeal in loose material and soak in bath water or buy oatmeal products.

Sorbolene and glycerine lotion twice daily for an itch caused by dry skin.

JOINT STIFFNESS

Encourage walking, bending, moving hands, arms, legs during the day. If not able to do this alone, carer gently gives passive exercises 3 to 4 times/day.

Massaging with oils is also helpful.

MOUTH ULCERS

If painful:

Drink through a straw to bypass the sore mouth.

Avoid spicy, acidic, sharp foods and citrus fruits.

Avoid toothpaste, instead use Bicarbonate of Soda in a thick solution and gently brush.

Gently apply teething gel or use chlorhexidine gluconate mouth rinse.

Use bicarb soda mouthwash as a gargle. Hold in mouth, swish and spit out.

Do at least 4 times daily.

Suck on chewable antacid tablets like Mylanta. Coats the ulcers.

Note: Ulcers due to thrush or virus - seek specific remedies from pharmacy,

ask your GP or Community Nurse

MOUTH WASH

1 cup boiled water, 1 heaped teaspoon Bicarbonate of Soda.

Mix and use frequently throughout the day. Gargle, swish and spit.

Use soaked gauze or large swabsticks to wipe inside of mouth if too weak to gargle.

NAUSEA

Very often caused by constipation. Relieve that first, then nausea will automatically go if this is the cause.

Timing of nausea helps you work out the cause. Morning nausea, on waking, is usually due to pooled mucous from sinuses being swallowed. This is relieved with chest physio or inhalations before bedtime at night. (See wet cough notes).

Cut meal sizes down to small snacks and eat earlier in the day.

Sit up whilst eating so regurgitation due to weak muscles is overcome.

Drink water between meals not with them.

Have a wide variety of snacks to tempt at any time.

Offering a dry cracker eaten before rising can help.

Sips of peppermint tea or ginger beer throughout the day.

PAIN

Pain is most often a symptom with several causes.

Understand pain as an experience of the whole person (body, mind, spirit)

For example, one may have cancer in an area of the body which is much more painful even to the point of being unbearable. Medications for the pain are just not working. What is happening here is that the pain is worsened because of feelings of fear, anxiety, or of not being understood. Therefore your loved one needs special help.

Talking out various aspects of life with a close friend, counsellor or minister of religion can often alleviate the pain dramatically without any change in medication. Often when this special approach is used, pain medication can be considerably decreased.

An Example.

John was a 79 year old man with pancreatic cancer. He had severe unrelieved pain despite the best palliative care. John just wanted to leave the hospice to return home, but his doctors would not allow this as he lived alone and they were deeply concerned he was unable to manage as he was very ill. On questioning him I found he had five children, all living afar but willing to care for him at his home. I knew that getting John home would solve his pain problem.

He went home in the care of his family and lived two weeks in comfort taking very small doses of pain medication only occasionally. His wish was to 'just float away on a cloud', which he did fully conscious to the end. The family gained so much from that experience as well as John getting his wish.

PAIN RELIEVING TECHNIQUES

Foot massage is very effective.

All parts of the body are represented on the sole of the foot. Hold the foot in the hands and massage each foot using your thumbs until you hit a sore spot. Keep massaging that spot firmly as tolerated and in a few minutes the pain elsewhere in the body will be relieved.

Relaxation exercises if practised well are the most powerful pain reliever.

This is the reason why relaxation exercises practiced 2 - 3 times a day needs to be 'in place' so that it can be as effective as possible as a pain reliever.

Imagery. Techniques to alter the sensation of pain, or move it around the body can be learnt. Experiment.

For example, each time you breathe out you can, by using your imagination, breathe out more and more of the pain until it has gone out of your body on the breath. Experiment and practise.

Similarly, in a state of deep relaxation some people find it is possible to move that pain from the spot where it hurts to another part of the body. Then it can even be walked off in the footprints. All done with imagery but that is why practiced deep relaxation is so helpful.

Other tips for pain relief

Often simply repositioning can help.

The painful area can be massaged very gently.

Heat packs are usually most comforting.

Deep slow breathing exercises.

Apply heat or a heat pad.

Request the loan of a Spenko mattress or Air mattress (best for back pain).

TENS machine. A small device applied to the skin which delivers a small electrical stimulus to that area of skin away from the painful area. It 'tricks' the brain into concentrating on another area where there is no pain.

All these suggestions for pain control are to help people take control and maximise their input. This means less medication is needed and fewer side effects from the pain medication, allowing more alertness and quality of life. As carer, when you have for example, a headache, you will know how to help yourself.

RATTLES

The cause is noisy mucous in chest. This can happen when your loved one is very sick and too weak to cough the mucous up. Often this occurs at a stage when your loved one is deeply sleeping. Although it can be loud it appears it is much more disturbing to us than the one who is very ill.

Gently move from lying flat to a more upright position, with head to one side. Positioning is helpful but do this as tolerated and only for comfort.

Gentle chest massage sometimes helps.

RESTLESSNESS

Talking calmly to your loved one.

Look at the environment. It may be too hot or cold or may be simply uncomfortable having been in one position.

It may be the need to go to the toilet that is causing the restlessness.

Take time to understand what or who the patient may be thinking about, getting confused over, or needing help with.

Reassure them that they are safe, that you are there and will not leave them alone.

Play gentle calming music of the patient's choice.

Gentle stroking from shoulders down to hands.

Guide them back to doing deep slow breathing, relaxing.

SHAKING

Check if too cold. Perhaps it is a fever beginning.

Deep breaths.

Relaxation exercises.

Gentle stroking from shoulders down to hands.

Reassure patient.

SKIN

BREAKDOWN AREAS

Best preventatives:

Repositioning.

Ensure one multivitamin tablet per day.

For skin already broken down use special overlay on bedding e.g. Spenko mattress.

Move into a waterchair or pillow to sit on.

Change position frequently during the day as tolerated.

SKIN DRYNESS

Wash in Aqueous Cream (use no soap). This is the best treatment.

Sorbolene and Glycerine moisturiser twice daily.

Pure medicinal olive oil (bought at the pharmacy) is effective.

SLEEPLESSNESS

Remember your loved one can't expect to sleep through the night if sleeping on and off through the day. Therefore:

Replace daytime sleep by providing interesting activities.

Have patient out of bed when possible sitting in another room.

Best sleep inducer is warm milk - with flavouring of choice.

Chamomile tea is a sleep enhancer. Pleasant with added honey.

RELAXATION EXERCISE FOR SLEEP.

Get into a comfortable position in bed. Decide to stop thinking.

Breathe deeply in and out saying this to yourself 'breathing in', 'breathing out'.

At the end of the full breath count 1, another full breath then 2, and so on to 10.

But if a thought comes into your head you must go back to counting 1.

It needs some practice but if you are conscientious with this it always works and no one gets as far as 10! Trust the process.

STOMACH ACHE

Peppermint water.

Decrease acidic or spicy foods and try a soft bland diet for a few days.

Eat small quantities of food.

Chamomile tea.

SWEATS

Sleep lightly covered at night, loose clothing if daytime.

Use a fan to cool the room air. (There is no risk of “catching cold”).

Mild warm water sponge.

If well enough take a shower. Water temperature has to be tepid not cold.

Then the effect of the cooling will last.

Sweating can occur with several types of cancer. It does not necessarily mean an infection. Also some medication causes this. There is no harm, just gain comfort by cooling down.

SWOLLEN LIMBS

Keep skin soft with oils and cream.

Elevate feet.

If an arm elevate on a soft pillow.

Very gentle massage of skin around the whole circumference of the limb moving hand in an upward direction towards the heart using cream or oil. Do this for a few minutes three times daily.

TOOTHACHE

Oil of Cloves applied directly to tooth (bought at the pharmacy). This numbs the pain.

THRUSH

Recognise this problem when you see white spots and areas on the tongue and in the mouth. It happens quite often and sometimes the sick person complains of soreness eating and especially swallowing. It is likely to occur in very sick people and with certain medications such as dexamethasone.

Gently brush tongue, teeth and gums with sodium bicarbonate solution three to four times per day. Use a weaker solution for swishing around mouth, holding and then spitting out.

Recipe: 2 teaspoons Bicarbonate of Soda with half cup of water, or make a thicker solution if required for very heavy thrush.

If persistent or painful you may need to purchase liquid or tablets from pharmacy. Your doctor will prescribe.

URINE THAT IS BURNING OR STINGING

Be alert to this symptom and act early.

Follow these suggestions as there may be no need to ask for antibiotics to treat an established urinary infection.

Make sure fluid intake is increased.

Decrease acid in the diet, fruits, spices, etc.

Drink pure cranberry juice or take cranberry tablets.

Ural Sachets can be bought over the counter at the pharmacy. Take 1 sachet four times a day, dissolved in a glass of water.

VOMITING

Encourage fluids once vomiting is settled.

Ice chips are often tolerated early on in the episode. Take a small teaspoon of finely crushed ice chips and hold in the mouth for a small time then swallow.

Cool water with slice of lemon to sip/weak tea.

Increase salt intake when able to take in a lot of water (e.g., small quantity of broth with a little salt in it to replace losses).

CONTROL PAIN - possible cause of the vomiting.

REVERSE CONSTIPATION - likely cause of the vomiting.

WHEEZE

Sitting up position.

Purse lipped breathing. Breathe in through nose and out through mouth as if going to whistle.

Nebulised saline. Borrow or rent a nebuliser if this is a new problem that is occurring, and nebulise four times daily or as required.

WOUND CARE

Saline solution bought or sterile water to cleanse.

Sterile water. To make, boil water for 5 minutes, then cool.

Hydrogen peroxide; a weak solution dabbed on will clean the wound.

If infected a honey product that is specially prepared can be bought at the pharmacy (e.g. MediHoney). Cover with a dressing. This is an excellent antibacterial.

If bleeding, first apply direct pressure with a finger if possible directly over the bleeding point. Hold the pressure for several minutes. This simple technique of direct pressure is the best first aid care to stop bleeding even if it is very active bleeding.

Then apply a pressure bandage. Use a thick sterile dressing that will not stick to the wound, then a firm bandage to hold it in place.

The Community nurse will provide care for serious wounds with specific dressings for odour/infection and healing.

Best room deodorisers are aromatic oils, incense sticks or simple candles.

“PATIENT ASSESSMENT”

- Check BODY FUNCTIONS - BALANCE - JOINT FLEXIBILITY - STRENGTH.
- Is he AWARE - MOTIVATED?
- What are the MEDICAL and ENVIRONMENT CONDITIONS?

GET SET -

- Assist only as needed to aid.
- Tell what you will be doing for transfer teamwork - step by step.
- Let him see destination during move.
- Give short, simple commands. *Encourage!*
- Transfer across shortest distance.
- Adjust furniture, bed height to advantage.
- Lock all wheels to avoid sudden shift.
- Use transfer belt for firm grip.
- Have him wear non-slip footwear.
- Have dry floor, clear path, lighted.
- Protect any drainage tube, IV, etc.

USE GOOD “BODY MECHANICS”

- Stand close, spread legs for balance.
- Bend knees, hips - lift with leg power.
- Start comfortably. Set body muscles to support spine during moves.
- Avoid twisting, jerking, bending.
- After - give muscles recovery time.
- **NEVER risk lifting too much! Get help or use mechanical aids.**
- Caution - no one transfer method can fit all conditions. **PLAN AHEAD.**



TOILET -

Ideally, chair is beside seat (a raised toilet seat makes sitting or standing transfer easier). Lower dothing first, then remove chair arm. He pushes on toilet seat and wall rail during transfer. Give support as needed.



TUB -

Have nonskid mat/strips in tub. At first, a chair inside tub is easier - later he can sit on bottom.



CAR -

Best to enter at passenger front seat.
Sitting transfer: Move feet in last, out first. You steady the chair, support as needed.
Standing transfer: Can grip door, car top, seat back.

ONE-TO-ONE ASSISTING



Basic Procedures for • Patient Transfer and

- Activities for Daily Living...

Here are basic procedures to be used under medical direction and adapted to fit each situation - conditions vary.

Give only the help that is needed.



TO SIDE -

- STEPS: a) First move legs to the side and cross arms,
 b) reach under, then
 c) "123-Pull." While pulling him back - shift your weight to back leg.



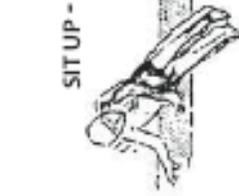
TO HEAD -

- a) he bends knees to push and raises head,
 b) your arms are under - inside leg steps back,
 c) "123-Pull." - shift weight to your back leg.



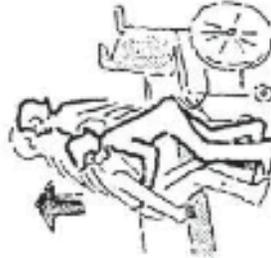
TURN -

- He is at far side,
 a) place arms as shown,
 b) leg is crossed over
 c) your hands grasp hip and shoulder - then
 d) "123-Pull."



SIT UP -

- Can he push up to short sitting position as shown?
 a) Or, he starts at edge on his side, knees flexed.
 b) reach over knees and under shoulder (or head).
 c) "123-Sit" - he pushes up as you pivot him in one easy motion.



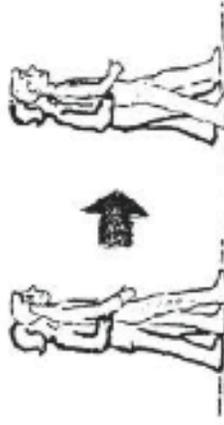
STAND UP.....SIT DOWN

- On edge of bed - he sees chair, leans over,
 a) "123-Stand" - lift by belt, knees touching - as he pushes up,
 b) you both pivot around,
 c) "123-Sit" - he holds chair as you both bend at knees and hip s.



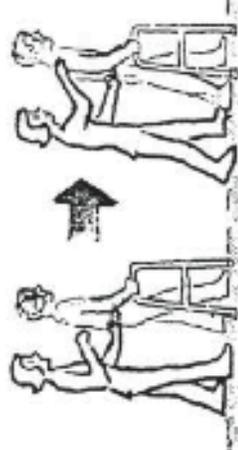
SLIDE.....TO CHAIR

- Place chair at bed, arm off.
 a) assist him toward chair,
 b) "123-Slide" - you lift by belt as he pushes back.



WALK - AT SIDE

- On weak side and slightly back,
 a) both hands can grip belt,
 b) together "Step" with opposite legs,
 c) "Step" again - helping only as needed. If he begins to fall, your outer leg steps back as he leans against you.



WALK - BEHIND

Stand in back.



DOWN

- Keep one hand on railing, while other hand free to give support/balance as needed (strong leg up first, down last).

UP