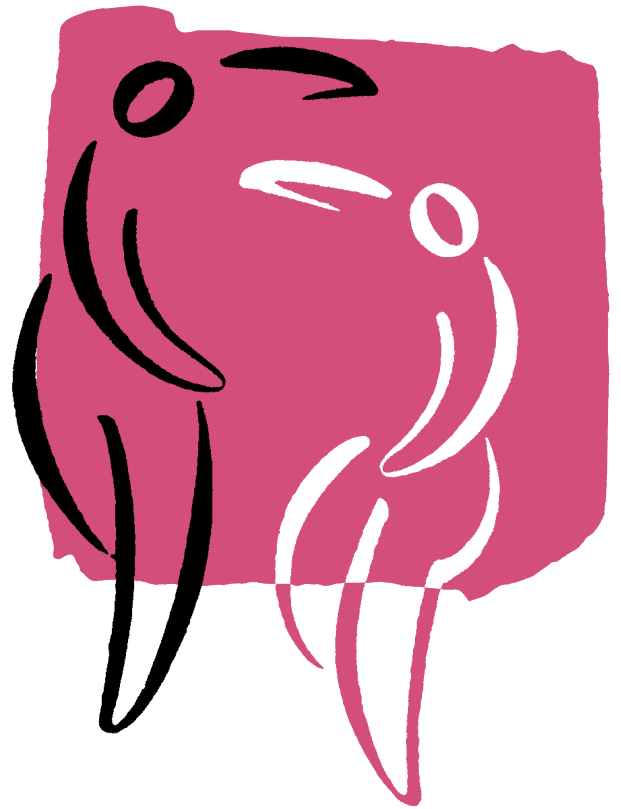


Rights & Responsibilities

for Carers

Family Carer Support Materials
Developing Carer Skills
A Resource Booklet



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Developing Carer Skills
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1 Introduction

Welcome to *Rights and Responsibilities for Carers*.

Rights and Responsibilities for Carers is not a training booklet but rather a support and resource booklet aimed at helping Carers face the many challenges associated with the caring role. Don't feel that you have to work through the booklet from beginning to end. Instead 'dip in' at those sections that best deal with needs and issues you currently face in your particular caring situation.

This booklet is one of three produced by the Carers' Association in South Australia. Like the other two in the series it isn't part of a formal study program. It does, however, provide the entry level skills needed for Community Services and Health courses offered by Registered Training Organisations. If, at a future date, you decide to undertake a certificate course/qualification your skills will be acknowledged if this booklet has been completed.



The aim of this resource is to:

- build on the skills and abilities we, as carers, already possess
- highlight particular issues likely to be experienced and explore ways for tackling them
- increase levels of confidence
- identify resources and organisations that can support and help us in our role as carers.

Did you know it has been estimated that there are 2.3 million carers in Australia – people like you who care for a spouse, partner, child, parent, friend, relative or neighbour because that person is not fully capable of supporting themselves? 2.3 million people who face challenges, rewards and difficulties that vary from day to day, week to week, year to year? Yet, despite the differences in particular situations, we all share the experience of having someone who depends on us; someone whose well-being relies on our being there and the carrying out of tasks that sometimes go beyond the normal role expected of a partner, friend or relative. And that's a very unique, special and often daunting experience.

2 About this booklet

As carers many of us get caught up in doing the ‘right’ thing either because it’s expected of us or because we expect it of ourselves. In the process it can sometimes be easy to ‘forget’ about our own needs. We focus on getting things done, on making sure that the day to day issues are taken care of to the best of our abilities. Yet, in order to cope with these daily demands we often put our rights, needs and thoughts aside. Unfortunately by doing this we can create problems later on... problems that will add to our stress and make our role harder. As carers it’s important that we’re aware of our rights, that we take the very positive step of planning for the future and that we recognise that sometimes our needs – and those of the person we care for – won’t be the same.

As you progress through this booklet you’ll see that the focus is very much on Carer rights –that’s not to say that our rights are the only ones to consider. They’re not. We also need to identify and respect the rights of the people for whom we care ... but we will focus on this in more detail in the booklet *Advocacy for Carers*.

This booklet is a guide to identifying and working through a number of these issues and is linked with the booklets:

- *Communication for Carers*
- *Advocacy for Carers*.

At the end of this booklet you will find a list of resources and organisations that offer further information, assistance, advice or referral.

3 Recognising our rights



‘Rights’ is a word we are all familiar with. We know that we have rights; that the people we care for have rights; that individuals within the wider community have rights.

But do we really know what our rights are and how those rights apply to the caring situation?

Activity

Think about the different rights people have. You may find it useful to list them below. (e.g. the right to say no; the right to ask for assistance etc.)

Once you’ve done so, identify the rights you have as a carer. Are they the same as the general rights you’ve described above? If there are any differences you might find it useful to write them below.

3 Recognising our rights

Do these rights differ from those of the people for whom you care?
Again, you may find it useful to note them in the space below.

Identifying rights in general isn't hard, is it? We have the right to privacy, the right to be treated with respect and dignity, the right to make decisions about the matters that affect us, the right to our own opinions, the right to complain and the right to access and receive information and to use public services (to name just a few).

Yet, as carers, most of us have probably realised that having our rights met isn't always as easy as it might seem.



“I was amazed at how refreshed I felt after taking a two week break from my caring role.”

3 Recognising our rights

Activity

Can you identify with one or more of the examples below? Select a scenario close to your own situation or like an experience you've had and think about your response.



- a) *You have been left out of discussions with the doctor/service provider about the treatment and care plan of the person in your care – treatment that has a major impact on how you organise your life.*
- b) *You are under 18 years of age and caring for an elderly relative or a disabled sibling, yet because you're not legally an adult and don't have any official rights, you're unable to sign documents, make legal decisions or have your complaints/suggestions/ or issues taken seriously.*
- c) *You had been living with your partner for over 15 years before they became seriously ill. The diagnosis is not good and the doctor and social workers keep asking to speak to 'members of the family'. The fact that you have been in a gay relationship with this person - and see yourself as their family – is ignored.*
- d) *You've mentioned, that after lunch is not a good time for the nurse to visit as this is when your father is tired and likes to sleep. You use this time to read, have a break, catch up with the household jobs and occasionally have neighbours in for a cup of tea. The nurse, however, states that she's in the area and this time suits her best.*
- e) *You're feeling tired, exhausted and in need of a few days rest. When you ask a family member to stay for a few days, so you can take a break, the person you're caring for says you're being selfish and that you see them as a burden.*
- f) *You're caring for a relative with a mental illness – a relative who doesn't always take their medication, which can result in violence. When you try to discuss the matter with the relative's doctor your fears and concerns are dismissed as exaggerated.*

3 Recognising our rights

In each of the situations above the carer's rights have been ignored. Yet not everyone will see this. Often we identify with the other person's point of view or we 'see both sides' of the situation. It is important that we see all sides but at the same time not lose sight of our own rights.

So, where should we go and what should we do if:

- we're unsure of our rights
- our needs/rights clash with the needs of other people
- our age, sexuality or cultural background appears to have been used against us?

Talking about conflicting rights and needs with the individuals/services involved is the key to building good relationships and making sure that our rights are met. This issue is looked at in more detail in the booklet *Communication for Carers*.

If, on the other hand, we believe our rights have been ignored we can contact a number of different organisations. A useful resource is *Your Rights and Responsibilities – A Charter for South Australian Public Health System Consumers*.

This booklet, along with information on your rights can be accessed by contacting the Carers Resource Centre on 1800 242 636 or by following up the resources or agencies listed at the end of this booklet.

4 What are our responsibilities?



Our rights as individuals and carers are very important ... but with those rights go responsibilities. If we're to be treated with respect then we need to make sure that we treat others with similar respect. If we are to make decisions for ourselves, we also have a responsibility to include those we care for in decisions that affect them (if at all possible).

Activity

Spend a few minutes thinking about your role as a carer. What responsibilities do you have? (Listening, washing, feeding etc.) You may find it useful to list your answer below.

If you were to discuss your list with other carers you'd find both similarities and differences. At one end the responsibilities will be extremely practical and include such things as washing, showering, toileting and grooming. If the person is more agile and physically able then the tasks we undertake may focus more on general activities - shopping, gardening and mowing the lawn. All of us, irrespective of the age and level of illness/disability of the person we care for, are responsible for listening, caring, comforting, supervising and supporting.

4 What are our responsibilities?

Sometimes, carrying out these responsibilities can present us with challenges. It may be that the person for whom we're caring:

- wants us to do things for them even though they can do it themselves
- tries to maintain their independence even though they are physically/intellectually unable to do so ... which creates more work for us
- needs constant, ongoing assistance
- resents our care
- constantly apologises for being a burden to us even though we don't see them that way
- believes they have skills they no longer possess
- takes us for granted.

So what should we do when these things occur?
(And for many of us they will.)



4 What are our responsibilities?

Activity

Think about your own situation. What difficulties or areas of concern do you face in managing your responsibilities?

Now think ahead twelve months. Are your responsibilities likely to change? Can you identify strategies to put in place so that responsibilities are not overwhelming?

4 What are our responsibilities?

Clearly the first thing we need to do is to be aware of all our responsibilities. Writing a list helps identify the tasks we do on a daily, weekly and fortnightly basis. And, once we've worked out what needs to be done, it becomes easier to:

- a) identify who could help take on these tasks (e.g. can the person we're caring for assist in some way? Are there other members of the family who could help out? Are there particular services or agencies we could approach for support?)
- b) plan our time so we can include time out for ourselves
- c) think ahead and prepare for issues before they arise (e.g. we know that our partner is growing more forgetful so we begin to look at the things they currently do – like manage the family budget – and organise for someone, perhaps ourselves – to gradually take on that task).

And we're not alone. For help, advice and more information refer to the list of resources and organisation listed at the back of this booklet.

5 Caring for ourselves



Recognising our rights and responsibilities as carers is not only important to our health and well being, it also impacts on the lives of those around us. Imagine that you're running a home, looking after children, maintaining a part time job and you're the main carer for an elderly, disabled or mentally ill family member. If you ignore your own personal rights and needs and try to meet everybody else's - this will soon take its toll on your motivation and health. And that will have a negative impact on the care you provide.

Activity

Think about your life over the past few years.

- a) *What changes have taken place since you've taken on caring for another person? (e.g. you don't work as much; you spend more hours at home or visiting the person who relies on you; you've stopped studying; you spend less time with friends or in social activities as your responsibilities to other people have increased; you've become frailer; your financial position has become less secure)*

5 Caring for ourselves

*b) What impact have these changes had on your health and well-being?
(e.g. difficulty sleeping; less enjoyment in life; feeling more alone; a sense of confusion; feeling as though you're valued and needed; forced you to think about your life and make changes, and greater closeness with your partner)*

Change is something that can't be stopped ... and although it can result in major challenges it's not always a bad thing. Our approach to change – how we see it and respond to it – has a major impact on our health and well-being. We can accept the change and make the best of it ... or we can focus on the past and try and maintain things as they were, which can lead to frustration and resentment.

Change affects us all. What we need to ensure is that those changes don't cause us to forget our own health and rights as individuals.



5 Caring for ourselves

Activity

Spend a few minutes reflecting on your life – not simply your life as it is now but your experiences over the years.

What sorts of things have you done that have made you feel good about yourself? (Think of the things that have helped you relax, made you laugh and given you enjoyment). You may find it useful to list your responses in the space provided.

Now focus on your life at the moment. Do you do any of these things? If not, why not?

That last question may sound a little harsh, particularly if almost every waking moment is spent caring for others. And lots of us are in that situation. But is it really impossible to do those things that used to give us joy and make us feel happy and refreshed?

5 Caring for ourselves

Activity

Choose any two of the positive activities you listed above and identify ways you could make these activities a regular part of your life.

Taking 'time out' and planning one off events is important. If we're to look after ourselves we need to take breaks that let us relax, be with friends and do things that add enjoyment to our lives.

Activity

Look at the next two months. What things can you plan on a weekly, fortnightly or monthly basis to look after yourself? (Try and be specific e.g. arrange for a neighbour/family member to be with the person you care for every Thursday evening from 6.00 to 9.00 so you can go out with friends.)

Arranging respite care (if you're not familiar with the word respite it simply means a period of rest or relief) is very important. There are many different ways of taking respite including having the person you care for visit a day centre or take part in a community activity (with their agreement of course), organising to have friends, relatives or volunteers offer in home care through to carer retreats and centre based care.

5 Caring for ourselves



At this point you may be thinking that these ideas won't work for me, particularly if you're facing family and cultural pressures. Remember: you're not alone. There are people and organisations who can help. For further information refer to the list of agencies at the end of this booklet.

If you're not sleeping and are tired, irritable and generally run down, visit your local doctor or community health centre.

You might also find some of the Commonwealth Government leaflets listed at the back of value.

Need a break?

Asking for help or advice doesn't mean that you're failing. On the contrary. Seeking out information and help shows that you recognise the need to stay healthy if you're to continue caring for someone else. If you decide to organise respite care – or if you realise that you can no longer cope on your own and you need alternative accommodation – you may experience feelings of guilt. This isn't unusual. Obviously we want to care for our friend, relative or partner to the best of our ability. If we can't or if we need to take either a short or long term break, then we must consider how their needs can be met.

Activity

Focus on your own situation and imagine that you are unable to care for your friend, relative or partner for a period of between four and six weeks. (It may be that you have to go into hospital or there is a crisis in the family). It's clear that you have to make other arrangements. List all the issues you would take into account when organising suitable care for your time away.

5 Caring for ourselves

No doubt you mentioned:

- the other person's wishes and feelings
 - the physical environment/location and atmosphere of the accommodation
 - making sure the organisation/paid carer, or alternative carer is familiar with the person's habits, likes, dislikes etc.
 - the attitudes of workers within the organisation (i.e. are they accepting of the person's cultural and religious beliefs? Do they acknowledge your lifestyle and friends? Are they welcoming and do they put the needs of the care recipients above 'rules and routines'?)
 - the sorts of activities and services they offer
- and, of course
- the cost.



Identifying these things in advance and making sure they are available makes it easier to leave the person for whom we care.

Of course, that doesn't mean that it's easy. The person may not want to stay with another family member or go into a respite accommodation. This issue is explored in the booklet *Communication for Carers*.

6 Creating a safe environment: caring at home



As carers each of us are in unique situations. Some of us care for people in our homes; others care for friends/relatives in their homes; while still others may share the responsibility with partners, siblings and family members.

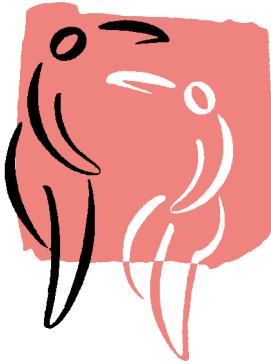
Caring for someone often begins as something we do out of love and affection. It doesn't always remain this way – particularly if we feel that we're bearing the responsibility alone. Sometimes our homes can add to, rather than reduce, the person's reliance upon us.

Activity

Think about your own situation. What things have you done – or could you do – to create a safe environment for the person for whom you care?

There are many practical ideas you could have made ranging from keeping the floors clear, making sure wires and cords are taped down, ensuring you have good lighting and placing handrails in the bathroom, toilet and on stairs and ramps. In making the environment safe we're encouraging the person to be independent and that, in turn, means that there is a little less need for us to provide constant supervision and support.

7 Developing short and long term plans



Although most of us make some effort to plan for the future, things don't always turn out as we intend. Imagine how much more difficult and complex life can become if we don't have a plan at all. What would we do if we were suddenly unable to care for the person for whom we have responsibility? How would we respond if they no longer tell us what they want or need? Or if they very quickly lost their physical abilities to a point where they needed almost constant care?

Do we have plans for the future? Do those plans go beyond the next few weeks and take into account such things as:

- finances
- legal issues
- emergency care
- life choices
- medical issues/choices?

Many carers may have a care plan that's been developed by the doctor or community/ worker outlining the health needs and available services for the person for whom we are caring. That type of plan is invaluable in that it gives us a base upon which to build. At the same time, it's important that we have a say into the overall plan. It's no good having a care plan based only on the needs of the person we care for without considering the impact it may have on you the carer.

7 Developing short and long term plans

Activity

Select one of the following scenarios and suggest how you might respond to the situation.

- You're under 18 and the primary carer for your mother who is suffering from multiple sclerosis. The doctor has developed a care plan and suggested that you take your parent to a service located 15 minutes away from your home. You cannot drive, your family is struggling financially and the 15 minute trip to the recommended service takes one hour and twenty minutes using public transport.*
- Your father-in-law speaks little English and is very traditional in his attitudes towards women doctors/nurses. The care plan doesn't take into account his values and feelings and relies on female workers providing him with assistance. As a result, your father-in-law refuses to attend medical appointments where the health professional is a female.*
- The care plan developed by your family doctor has been in place for over three years and has worked well. Recently you've noticed that the person you care for has begun experiencing brief periods of confusion. You mention this to the doctor but your relative denies this is happening. The doctor accepts their word and doesn't offer additional help or modify the overall plan.*

If you believe the care plan developed for the person for whom you care isn't right for them or for you, it's important to talk about the matter with the people concerned. You could also contact the Carer Resource Centre on 1800 242 636 and speak to staff about the issues that are worrying you.

7 Developing short and long term plans

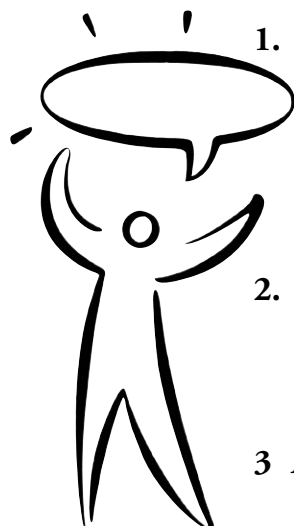
Looking at the future

In an earlier activity you thought about the criteria you would consider if you were arranging care for a short period. But what would you do in a sudden emergency? Do you have a plan in place?

Activity

If you don't already have an emergency plan now is a good time to develop one. If you do, you might like to take this opportunity to check that it still reflects your current situation.

In developing your emergency plan think about:



1. The person you care for:

- their needs
- their abilities (what can they do for themselves)
- their weaknesses (what they can't do; what might go wrong)

2. Existing support people and services

- what do these people currently do?
- how can they be contacted?

3 Areas that aren't covered

- are there gaps between what the person needs and the support services/people you currently use?
- if there are, can you identify individuals or agencies who may be able to fill them?

If you require help in developing an emergency care plan you may like to:

- ring the Carer Resource Centre on 1800 242 636,
- the Carer Respite Centres on 1800 059 059
- your local Carer Support Group (the Carer Resource Centre can assist you in finding a group close to where you live) or
- access the *Emergency Care Kit* – the Carer Resource Centre has copies available which can be sent to you.

8 Giving medication

Although most of us aren't trained in the medical field we will, sometimes, be responsible for giving the person for whom we care their medication. Of course, we don't do so without guidance. The doctor will instruct us as to how, when and where a particular quantity of medication should be given – information that is usually provided during our discussion of the care plan. If possible, we should try to have these details written down.

Yet, as you know, giving someone medication isn't always a straight forward task. The person might not want to take it. Or they may take it and develop disturbing side effects. Or they may mix their medication with alcohol. Then too, we probably want to know exactly what the drug is for and how it will affect their behaviour. These important issues are discussed in the booklet *Communication for Carers*. In the meantime, if you have questions or queries about any aspect of giving the person their medication you should speak to the prescribing GP. Or, if you require help in administering the medication contact your local RDNS service for support.

9 Carers and the law



For most of us the law is something we don't really think about. We may get a speeding fine or read about crimes in our area but basically we're focused on our daily activities and caring for others.

Understandable though that may be, it's a mistake not to think about the law and what might happen if:

- the person we're caring for suddenly dies and hasn't left a will
- the person becomes mentally confused and can't sign documents or make legal decisions ... if they haven't arranged for us to do this while they are able then problems will arise
- medical decisions need to be made and the person hasn't given written authority for us to represent them.

For some people, these discussions can be very awkward. We may worry that it looks as though we're worried about our own interests if we bring up the subject of wills or possessions with people for whom we care. We may live in their home and look after them 24 hours a day but that doesn't mean that if they die without a will that we will be recognised when their house and belongings are distributed.

9 Carers and the law

Activity

The following situations are based on fact. Do you think they were resolved fairly? If not, how do you believe things could have been handled differently?

a) *Meredith, aged 43, had been employed full time as a hairdresser before her mother's illness. Given that she was the only child living in the state – her three brothers were scattered around Australia – she reduced her work load to one afternoon a week so she could provide her mother with the necessary care. Eventually her mother's condition got worse to the point where she needed full time support so Meredith left her job and moved into her mother's home.*

Eighteen months later her mother died and Meredith found that her mother hadn't made a will. Her brothers, only one of whom came to the funeral, made it clear that they expected the house would be sold and that all proceeds would be divided equally between the four siblings.

Her brothers received an equal share of the financial settlement.

9 Carers and the law

b) *Seventeen year old Alan had an mild intellectual disability and schizophrenia. Although his mother was his principal carer, Alan's older sister, Gen, was involved in his care on a daily basis. When Alan's mother died in a car crash it was revealed that she had left a large sum of money to be used for Alan's care and well-being. Gen believed this would be best achieved by placing him in sheltered accommodation. Her sister, Nikki, disagreed, arguing that it was important Alan remain with the family. She volunteered to take care of Alan. Two years later Alan's money had been spent – on Nikki's new car and house extensions – and Alan himself had little quality of life beyond the time he still spent with Gen.*



“Thank goodness my son thought he was a legal eagle, because he was able to help.”

9 Carers and the law

c) *Maria knew her illness was getting worse and decided, that the best thing she could do, was organise her will and ensure her children were given Enduring Power of Attorney (this is the legal authority to make decisions on someone else's behalf if something happens to them and they are not able to exert this power themselves). Fortunately the disease's progress was slower than anyone expected and so this precaution wasn't immediately necessary.*

In the meantime her family's situation changed. One of her daughter's moved overseas and her son had a major argument with her youngest daughter, Maurissa (her principal carer) and refused to visit the family home. When Maria did become very ill and quick decisions were needed a problem emerged because ALL three children had been given Enduring Power of Attorney but only Maurissa could be contacted and although she had her mother's best interests at heart she was legally unable to manage her mother's affairs.

Stories such as these highlight the problems that can occur if we don't take legal matters seriously.

There are a number of steps that can be taken by the person you care for to ensure their wishes will be respected in the event of either a death or a mental incapacity where they can no longer sign legal documents. Wills indicate the persons wishes after death, Advance Directives are used while the person is still alive.

9 Carers and the law

The following Advance Directives are available in South Australia and they are legally binding documents that come into force when a person is alive, but unable to fully understand what it is they are either signing, or if they are unable to communicate their wishes in any manner whatsoever.

They are Enduring Power of Attorney which covers financial and legal affairs; the Enduring Power of Guardianship covers medical and lifestyle decisions and the Medical Power of Attorney and Anticipatory Direction that cover medical and treatment decisions. It may seem a complicated process deciding which Advance Directive the person actually needs. For more information on Advance Directives see the contact list at the back of this booklet.

Activity

Think of your own situation and work through the checklist that follows.

a) Do you have a will? **Yes / No**

If you don't, you need to be aware that if you die without one:

- i) the government will decide who gets your possessions
- ii) the Guardianship Board (a government authority) will determine what happens to someone in your care if they are an adult with a mental incapacity and
- iii) the family court will determine what happens to children under the age of 18 ... (if alternative provisions haven't been arranged)
- iv) other people will decide whether you're cremated or buried and the nature of your funeral service.



To find out more about making wills refer to the information included at the back of this booklet.

9 Carers and the law

The Legal Services Commission also publishes a small brochure on wills explaining the advantages and disadvantages of writing your own will, hiring a solicitor or employing a Public/Private trustee.

b) Does the person you care for have a will? **Yes / No**

If they haven't, this could lead to problems in relation to:

- i) the family home
- ii) the distribution of their assets – e.g. superannuation, savings, shares, investments, jewellery, furniture
- iii) funeral arrangements.

If you know that the person hasn't written a will you need to encourage them to do so. We return to this issue again in the booklet *Communication for Carers*.

c) Does someone trustworthy know where your will is located? **Yes / No**

Is a copy located in a safe place? **Yes / No**

Making a will is extremely important ... but if no-one knows where to find it there's not much point in having one.



9 Carers and the law

- d) Have you given anyone Power of Attorney? **Yes / No**

Power of Attorney is a legal document that allows another person to act on your behalf. This power only applies if you are of sound mind. Essentially it allows you to 'share' responsibility with someone you trust (i.e. they can operate your bank account and buy and sell things for you). If you were to become mentally incompetent or unable to make your feelings and beliefs known then this power no longer applies.

- e) Have you given anyone Enduring Power of Attorney? **Yes / No**

Enduring Power of Attorney is more extensive than Power of Attorney because it continues to operate even if you are unable to communicate or if you become mentally incompetent.

If you haven't decided upon an Enduring Power of Attorney:

- there is no-one to manage your financial affairs should you become unwell. This can then result in lengthy delays; in-fighting between various relatives; additional burdens for the people who are caring for you.

For further information about deciding upon an Enduring/Power of Attorney refer to the information at the back of this booklet.

9 Carers and the law

- f) If the person you're caring for is above the age of 18 and of sound mind have they decided upon an Enduring Power of Attorney? **Yes / No**

If they haven't, it's important that you discuss the topic with them. This will make matters easier for everyone and will prevent you – or members of your family – applying to the Guardianship Board to appoint someone to take on responsibility for their concerns.

- g) Have you – or the person you care for – given anyone Medical Enduring Power of Attorney, made out an Anticipatory Direction or given an Enduring Power of Guardianship? **Yes / No**

The Enduring Power of Guardianship allows you to give someone authority to make medical and lifestyle decisions on your behalf. If you haven't, it means doctors and medical professionals will decide on the nature of your medical treatment. Occasionally this results in people receiving medical treatment they don't wish to have.

To find out more about medical consent refer to the organisations listed at the end of this booklet.

Making sure that we – and the people we care for – have taken steps to plan for the future is one of our most important responsibilities. Talking about the issues now and involving other friends/family members isn't being negative. It's actually making sure that everyone knows what the person wants ... and that knowledge can make the times ahead less stressful.

10 Financial matters



Although money can give great pleasure it also has the ability to cause great distress and upset. A person's finances are seldom simple even when they live on their own. There's the mortgage/rent, bills, living expenses, insurance costs, health benefits, taxes etc. For many of us caring for another person may mean at least one of the following:

- having to learn about money matters ourselves (because the other person has always taken care of this aspect of the living arrangements)
- handling the financial side of the other person's affairs
- trying to deal with many new and frightening issues.

Activity

Think about your own situation for a moment.

- a) Who currently manages the household/family expenses?
- b) Do you know:
 - where the lease agreement/home ownership papers are kept?
 - the location and extent of the various insurance policies? i.e.
 - i) household
 - ii) car
 - iii) medical benefits
 - iv) income protection
 - where to find the person's tax file number? (if they have one)
 - the benefits/payments they receive and any legal obligations the person has to notify the organisation/agency about any change in status?
 - the location and nature of their credit cards?
- c) Do you feel totally confident handling the other person's finances?

10 Financial matters

Making sensible financial decisions isn't easy given the complexity of things like international exchange rates, fees, changing share prices, goods and services charges. If the area is new to you it's important to get accurate, timely and appropriate information from people with skills in the area. Friends and relatives may be well meaning with offers to assist, but your financial future is too important to be left to risk.

To find out about organisations and resources providing assistance in relation to financial matters refer to the lists at the end of this booklet.

Activity

Consider the scenario below. How could the conflict involving financial matters have been avoided?

Jackson had lived with chronic health problems for a number of years and yet managed the family's finances from his ground floor flat. One day, he suffered a major stroke and from that point on was unable to make decisions about any aspect of his life – money and medical treatments being key areas as far as his wife and family are concerned. Almost all their possessions were in his name (car, house etc). His wife, Carole, and daughter, Evelyn, know what he wanted as far as medical treatment and accommodation - though he hadn't written anything down. His children from a previous marriage disagree. The last few months of his life are spent arguing with his wife, who devoted herself to his care, and with his older children who are opposed to any 'big' spending to make his last months more comfortable.

11 Final matters

Many of us are familiar with the term ‘palliative care’ – essentially it means providing support for someone who is in the last stage of an incurable illness. Palliative care is about life rather than death. But not everyone who is dying wants their life to be maintained using artificial means.

Activity

Q: If you were dying - would you want the medical profession to take special efforts to keep you alive?

Q: Now consider the person for whom you care - would they prefer to be kept alive at all costs or would they rather die naturally?

Q: Do both you and the person for whom you care share the same feelings about palliative care? If you haven't discussed this issue it's very important that you do – and that other people who play a significant role in the person's life understand the person's wants and needs.

There have been many cases where a well meaning family member or carer has supported the use of life-sustaining measures and had their efforts condemned by the person concerned.

To find out about Anticipatory Directives – which is where a person specifies what they want to happen in these situations and/or appoints a representative to make decisions on their behalf if unable to do so – refer to the list of contacts at the back of this booklet.



12 Conclusion



As carers it isn't always easy standing up for our rights

as individuals or confidently carrying out our responsibilities. It would be foolish of us to state that it is. Caring for someone isn't something we do without considering the impact. On the contrary. It's one of the most complex and challenging roles we can take on. When we're responsible for someone else we do far more than cook meals and pay bills. We deal with the real person: their fears, hopes, dreams, needs, desires and ambitions. And we don't just do this once, but on a daily basis. Then too, we have to our own feelings – feelings that will change over time.

Asserting and applying our rights and responsibilities against this background of emotion can be difficult. But although it's hard at times to stand up for ourselves and to raise painful issues about wills, respite care and finances, it's something that has to be done. If we don't deal with these things now we're only delaying matters. And things won't get any better.

Talking with the person for whom we care, other family members, doctors and service providers *now* means that everyone can be involved in planning for the future. And, in the long run, that not only saves stress and heartbreak, it can also give others a greater sense of what's happening.

Our rights and responsibilities are too important to ignore. As carers we play a very significant role in people's lives. Yes, it can be tiring, exhausting, frustrating and demanding. But if we recognise that we have rights and we talk about those rights – and responsibilities – with others, we're helping (in a small way) to make people around us aware of the valuable role carers play.

13 Resource listing

Useful resources

Information on Caring

- Carers Association of SA
- Carer Information Kit

Available from

via the Carer Resource Centre
1800 242 636 *Carer Resource Centre*

-
- Information for Carers Fact Sheets

1800 242 636 *Carer Resource Centre*

-
- The Carer Interviews – Programs 5 - 9

Carers of the aged
Multicultural carers
Men as carers
Carers of the disabled

1800 242 636 *Carer Resource Centre*

-
- Carer Contacts:

a quick guide to assistance for Carers

1800 242 636 *Carer Resource Centre*

-
- The Carer Experience –

Information & ideas for carers
of people with dementia

1800 242 636 *Carer Resource Centre*

1800 639 331 *The Alzheimer's Association*

Information relating to rights

- Your Rights and Responsibilities

A charter for SA public health
system consumers

1800 242 636 *Carer Resource Centre*

-
- Carer Contacts:

a quick guide to assistance for Carers

1800 242 636 *Carer Resource Centre*

-
- Aged Rights Advocacy Service publications

Participation in Decision Making
Getting it Right; Prevent Abuse

1800 700 600 *Aged Rights*

Advocacy Service

Caring for ourselves

- Carers Relaxation: information for Carers
tape / CD

1800 242 636 *Carer Resource Centre*

-
- Information for Carers Fact Sheets

Taking a break
Taking Care of Yourself
Feelings
Services for You
Respite Care

1800 242 636 *Carer Resource Centre*

-
- Joe's Diary - A SANE guide for young people
who have a family member with a mental illness

www.sane.org/bookshop

13 Resource listing

Useful resources

Caring safely at home

- **Home Safe: A guide to first aid and staying at home** 1800 242 636 *Carer Resource Centre*
by WorkCover - not a comprehensive publication

- **Information for Carers Fact Sheets** 1800 242 636 *Carer Resource Centre*
Safety at home
Managing Health Care and Medication

- **Inpharmation** 1800 242 636 *Carer Resource Centre*

- **Carers Home Safety Checklist** 1800 242 636 *Carer Resource Centre*

- **How to Care Safely at Home** 1800 242 636 *Carer Resource Centre*

- **The Carers Pathway** 1800 242 636 *Carer Resource Centre*

- **Carers Handbook: a practical guide to caring for people who are sick, elderly or disabled** 1800 242 636 *Carer Resource Centre*
1800 246 850 *Australian Red Cross*
1800 182 131 *St John Ambulance*

Developing long and short care plans

- **The SANE Guide to Planning Ahead: a guide for Carers of people with a psychiatric disability** www.sane.org/bookshop/home/php

- **Information for Carers Fact Sheets** 1800 242 636 *Carer Resource Centre*
Financial Assistance
Legal Arrangements

- **Emergency Care Kit** 1800 242 636 *Carer Resource Centre*

- **A Carers Handbook** 1800 242 636 *Carer Resource Centre*

- **The Carer Experience** 1800 242 636 *Carer Resource Centre*

- **Dept of Health Aged Care pamphlets** 1800 242 636 *Carer Resource Centre*
Staying at Home: care & support for older Australians
Aged Care High Quality Residential Care
Aged Care Assessment Teams
Community Aged Care Package: your right to quality care

- **Aged Rights Advocacy Service pamphlets** 1800 700 600 *Aged Rights Adv. Service*
Pathways to accessing home based services

13 Resource listing

Useful resources

Carers and the law

- **Information for Carers Fact Sheets** 1800 242 636 *Carer Resource Centre*
Legal arrangements

- **The Carer Interviews** – Programs 1-4 1800 242 636 *Carer Resource Centre*
Carers and Legal Complexities
Power of Attorney
The Guardianship Board
Wills and Funerals

- **Enduring Power of Guardianship:** 1300 366 424 *Legal Services Commission*
a do-it-yourself kit 13 23 24 *Service SA*
www.service.sa.gov.au

- **Enduring Power of Attorney:**
a do-it-yourself kit

- **Legal Services Commission of SA pamphlets** 1800 242 636 *Carer Resource Centre*
Power of Attorney
Wills
Enduring Power of Attorney

- **Office of the Public Advocate pamphlets** 1800 242 636 *Carer Resource Centre*
What is the Office of the Public Advocate? 1300 366 424 *Legal Services Commission*
What is the Guardianship Board? 13 23 24 *Service SA*
What is a Guardianship Order?
What is an Administration Order?
Informal Arrangements
Enduring guardianship and other future plans
Consent to medical & dental treatment for persons with reduced mental capacity
Where to go

Financial matters

- **A guide to Commonwealth Governments Payments** 13 27 17 *Centrelink*
www.centrelink.gov.au/Internet/Internet.nsf/publications/Index.htm
1800 242 636 *Carer Resource Centre*

- **Information for Carers Fact Sheets** 1800 242 636 *Carer Resource Centre*
Financial assistance
Managing Money

- **Financial Checklists** 08 8303 0590 *Women's Information Service*
1800 188 158 www.wis.sa.gov.au

13 Resource listing

Useful resources

Final matters

- **Caring for a Dying Relative or Friend** 08 8291 4137 *Palliative Care Council of SA*
 - **Caring for a Grieving Friend** 1800 660 055 *www.pallcare.asn.au*
 - **We Who Care**
 - **We Who Grieve**
-
- **Dealing with Dying** 08 8291 4137 *Palliative Care Council of SA*
-
- **What is an Anticipatory Directive?** 13 23 24 *Service SA*
1300 366 424 *Legal Services Commission*
-
- **What to Do When Someone Dies** 13 27 17 *Centrelink*
-
- **The Carer Interviews – Program 4** 1800 242 636 *Carer Resource Centre*
Wills and Funerals

13 Resource listing

Organisations

For information and assistance relating to your rights

• Carers Association of SA	1800 242 636 <i>Carer Resource Centre</i>
• Carer Resource Centre	1800 242 636 <i>Carer Resource Centre</i>
• Carer Support Groups	<i>Carers Resource Centre can refer you to your local group</i>
• Health Ombudsman	08 8226 8699
• Welfare Rights Centre (SA)	08 8266 4123
• Legal Services Commission	1300 366 424
• Aged Rights Advocacy Service	1800 700 600 08 8232 5377
• Community Information Services	08 8303 0590
• Disability Complaints Service	1800 088 325 08 8234 5699
• Mental Health Resource Centre	08 8221 5166
• Migrant Resource Centre	08 8217 9500
• Nunkuwarrin Yunti of SA advice and advocacy for Aboriginal people	08 8223 5217

For advice on respite care, personal support and self care

• Carer Resource Centre	1800 242 636 <i>Carer Resource Centre</i>
• Carer Respite Centre	1800 059 059
• Carer Support Groups	<i>Carer Resource Centre can refer you to your local group</i>
• CARA Community Accommodation & Respite Agency	08 8347 4588
• IDSC Intellectual Disability Services Council	08 8267 5966

13 Resource listing

Organisations

For advice on respite care, personal support and self care *continued*

- | | |
|---------------------------------|---|
| • Options Coordination | 08 8366 7333 |
| • Mental Health Resource Centre | 08 8221 5166 |
| • Seniors Information Service | 1800 636 368 www.seniors.asn.au |
| • Office for the Ageing | 1800 819 961
08 8207 0522 |
| • Commonwealth Carelink | 1800 052 222 |

For advice on creating a safe environment

- | | |
|-------------------------------|---|
| • Carer Resource Centre | 1800 242 636 <i>Carer Resource Centre</i> |
| • Independent Living Centre | 08 8266 5260 |
| • Seniors Information Service | 1800 636 368 www.seniors.asn.au |
| • Veterans Affairs | 08 8290 0568
13 32 54 |

For advice on accommodation options

- | | |
|--|---|
| • Carer Resource Centre | 1800 242 636 <i>Carer Resource Centre</i> |
| • Carer Support Groups | <i>Carer Resource Centre can refer you to your local group</i> |
| • CARA Community Accommodation & Respite Agency | 08 8347 4588 |
| • IDSC Intellectual Disability Services Council | 08 8267 5966 |
| • Options Coordination | 08 8366 7333 |
| • Mental Health Resource Centre | 08 8221 5166 |
| • Seniors Information Service | 1800 636 368 www.seniors.asn.au |

13 Resource listing

Organisations

For legal advice relating to wills

- Legal Services Commission 1300 366 424

- Community Information Services 08 8303 0590

- Public Trustee Office 1800 673 119 www.publictrustee.sa.on.net
08 8226 9204

- Your Local Neighbourhood or Community Centre
- A private trustee company
- Your lawyer or solicitor (if you have one)

For legal advice relating to Enduring Power of Attorney and Guardianship

- Office of the Public Advocate 1800 066 969 www.opa.sa.gov.au

- Public Trustee Office 1800 673 119 www.publictrustee.sa.on.net
08 8226 9204

- Legal Services Commission 1300 366 424

For information on Medical Power of Attorney or Anticipatory Direction

- Office of the Public Advocate 1800 066 969 www.opa.sa.gov.au
08 8269 7575

- Public Trustee Office 1800 673 119 www.publictrustee.sa.on.net
08 8226 9204

- Palliative Care Council of SA 08 8291 4137 www.pallcare.asn.au

- Your Local GP

13 Resource listing

Organisations

For information on financial matters

- Your bank or financial advisor www.opa.sa.gov.au
-

- Carer Resource Centre 1800 242 636 *Carer Resource Centre*
-

- Centrelink 1800 686 126

For information on Anticipatory Directives

- Your GP
-

- The Palliative Care Council of SA Inc 08 8291 4137
-

- The Royal District Nursing Service 1300 364 264
-

- Your local doctor

The Carers Association of SA can help follow up issues or complaints regarding care treatment. However, if you need advocacy help relating to issues concerning your cultural background, age, sexuality or a particular disability - consider contacting one of the agencies listed above for help.



DEPARTMENT OF
HUMAN SERVICES



Carers
Association
of SA Inc.

14 Evaluation **Rights & Responsibilities for Carers**

You have now got to the end of the support materials to develop your skills in 'Rights & Responsibilities'.
The only way in which these materials can be improved in the future is through your feedback.

1. Could you please take a few minutes to respond to the following questions:

- Please rate your **skill level** on this topic **prior** to completion of these support materials

(1 = very poor; 2 = poor; 3 = OK; 4 = good; 5 = very good)

1 2 3 4 5

- Please rate your **skill level now** that you have completed these support materials

1 2 3 4 5

- Please rate your **knowledge level prior** to completion of these support materials

1 2 3 4 5

- Please rate your **knowledge level now** that you have completed these support materials

1 2 3 4 5

2. Please comment upon the content of the support materials:

- Were they easily understood? **YES / NO**
- Could you find the section that was relevant for you? **YES / NO**
- Did they assist you to learn? **YES / NO**

3. Please describe the aspects of these materials that were most helpful to you?

4. Were there aspects of the support materials that were not helpful to you?

5. Were there things missing from the support materials that would have been useful for you?

6. Would you like to see other things developed in this way to assist you in your role as a primary carer?

Thank you for your involvement ~ once completed please send this to the Carers Association of South Australia at admin@carers-sa.asn.au, or mail it to PO Box 410, Unley, SA, 5061 or fax it to 08 8271 6388.

