

Advocacy

for Carers

Family Carer Support Materials
Developing Carer Skills
A Resource Booklet



Who is a carer?

A carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.

Carers come from all cultural and social backgrounds and range greatly in age, from children to the elderly. They give up their time, their income and resources to care.

Caring for someone is challenging, demanding and occasionally frustrating. But then so are many of life's meaningful events and experiences. And, just as there are days of stress and anxiety, so too are there times of joy, warmth and closeness. Of course there are obstacles and difficulties - this booklet focuses on strategies for minimising their impact. At the same time, however, there are also unexpected rewards ... rewards as unique and individual as the relationships we form and the interactions we develop.

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Disclaimer
This booklet does not provide legal or any other professional advice. If you need professional help, you should go to the appropriate person (eg lawyer or general practitioner). Contact information can be found at the end of this booklet.



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1 Introduction

Welcome to *Advocacy for Carers*.

Advocacy 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 required 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 as a carer will be acknowledged.



The aim of this resource is to:

- build on the skills and abilities we, as carers, already possess
- highlight particular issues we're likely to experience and explore ways we can deal with them
- increase 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 ourselves who care for a spouse, partner, child, parent, friend, relative or neighbour because that person is not able to care for 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 our 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

Caring for other people can be rewarding, challenging and unpredictable. At times we'll enjoy the experience and value our time with the person. Other times things may seem tough – it may be that despite our best efforts there is a lack of support from others; or that doctors, social workers and other family members aren't taking the person's condition as seriously as we believe they should. It may be that our rights are being ignored or overlooked.

The issue of rights and responsibilities, discussed in another booklet of this series, is important to this topic. When we speak up for someone we do so because we feel that things are unfair or that more needs to be done.

In the unit *Rights and Responsibilities* we look at our rights as carers. In this booklet we focus more on the rights of the person in our care. There will be times when their needs are not met and their rights as individuals are ignored. Sometimes we too will find ourselves dismissed or unacknowledged. The ability to take a stand and present our view/or that of the person for whom we care is a skill we should value and encourage in all carers. Put simply, if we don't speak up, who will?

This booklet is linked with two other carers' guides:

- *Communication for Carers*
- *Rights and Responsibilities 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 Advocacy – what does it mean?



‘Advocacy’ isn’t a word we’re likely to hear everyday.

We may know that there’s an ‘Office of the Public Advocate’ or an ‘Aged Rights Advocacy Service’ but most of us don’t come upon the term every day. Yet, even though we may not be familiar with the term, many of us put the basic principles into practice most days. Whenever we speak up for someone or represent their interests we’re acting as their advocate.

Activity

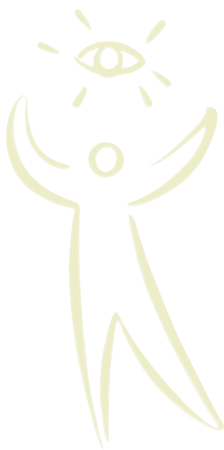
Reflect on your own behaviour over the past one to two weeks. Did you ‘take a stand’ on some topic or issue during this time? (For example, have you ever contacted a shop and complained about poor service or a problem with the goods you bought? Did you make a phone call to an organisation and ask for more support or changes to some aspect of care? Did you speak up when other members of the family ignored your point of view?) If you did, describe what happened and how you handled the situation below.

Most of us ‘advocate’ for our rights and what we believe in if we feel unhappy with the way we have been treated. But it’s not always easy. We worry that people will think we’re ‘pushy’ or selfish or inconsiderate. We may have trouble putting our thoughts into words – particularly if the people we’re talking to have professional backgrounds or if they appear confident and articulate. As a result we may not always speak up when we should ... or we don’t present our case as well as we could.

3 Advocacy – what does it mean?

Activity

Read through the case studies below. Can you identify with any of the situations? If you were in the carer's place would you 'take a stand'? Why? What issue would you address? What outcome would you want to achieve? If possible, describe what you'd do to achieve that result.



a) Brenton, Jessie's 14 year old Aboriginal son, is passionate about basketball. Although he has severe cerebral palsy, Jessie wants him to lead as normal a life as possible. Brenton's GP has been supportive and has told both mother and son that playing sport would be very good for Brenton – although changes to games and rules would need to be made. The school, however, refuses to allow Brenton to play any sport stating that they would be legally liable if they put Brenton and other children at risk.

3 Advocacy – what does it mean?

c) Jonathon is 85, legally blind, is partly paralysed as a result of a stroke and often has aches, pains and illnesses. His daughter, Heather, is his primary carer. Recently Jonathon's doctor changed his medication, saying that the new drugs could reduce a number of Jonathon's health problems. Within days of taking the new tablets Jonathon began complaining about 'noises in his head', dizziness and feeling sick. Heather rang Jonathon's doctor but the GP dismissed her worries saying that the new drug would take a while to 'kick in' and that Jonathon should keep on with the medication for at least a month.

3 Advocacy – what does it mean?

d) Eva is 26 and suffers from depression. Since her mother recent death Eva has started talking of suicide. Her sister Jackie, has tried contacting Eva's mental health worker but is told she is on holidays. The worker she speaks to suggests that she's worrying unnecessarily and is perhaps exaggerating the suicide concern. She suggests that Eva see her local GP or follow up with Eva's worker when she returns from holidays (in a fortnights time). Jackie knows Eva will refuse to visit the GP and feels the situation is more serious than the worker believes.

In each case a professional has ignored a person's rights or opinions. This isn't an uncommon situation. As carers we – and the people for whom we care – may have our rights, opinions, and needs overlooked and made less important by agencies, organisations, individuals and families. It doesn't happen all the time. And, for some people it doesn't happen very often or at all. However, the reality is that some of us may at sometime experience situations that involve insensitivity, prejudice, hostility, arrogance or a total disregard for the needs of the person in our care.



“I remember the moment when I realised that it was up to me to change things for myself.”

3 Advocacy – what does it mean?

So what should we do? To begin with we need to be clear that we have rights – and that those rights include being treated professionally and with respect. If our rights are ignored or we're unhappy with an aspect of the service we've received then we have a right to comment on (or complain about) the treatment. Some organisations, such as Home and Community Care (HACC), have policies and procedures relating to complaints and customer feedback and as consumers we can ask for copies of those materials. If an agency doesn't have a formal process in place and/or we're not sure what to do then contact the Carers Association's information service for advice and referral.

The next question, of course, is how do we advocate for someone who has been ignored or treated unfairly?

The first step, as you probably mentioned, is to take the person's 'side'. If we're advocating for someone – or something – we take a specific view and attempt to get that 'view' across to the other party.

Our concern has to be:

- the person for whom we care
- ourselves.

But given that advocacy means standing up for a person's rights we do have to be clear about:

- what those rights are
- what the person we care for wants
- whether they can advocate for themselves (it would be patronising of us to stand up for the other person when they are willing and able to do so for themselves)
- the best way of advocating for that person (e.g. what do we need to do? How can we do it?)

3 Advocacy – what does it mean?

Activity

Look at the case studies above and think about the following questions:

- Can the person being cared for advocate for themselves?
- If they can't, how do we find out what they want?
- What would be the best way for dealing with the situation – e.g. do we write a letter, phone the school/manager, make an appointment to see the person responsible?



What about roles and responsibilities?

Before we advocate for someone else it's important that we make sure that they want us to become involved. Imagine how you'd feel if someone kept stepping in on your behalf or talking to other people about your treatment without asking you. The key principle underlying advocacy is ensuring people's rights are upheld. However as carers, we need to think carefully about whether we are helping or, perhaps taking away the other person's rights. We need to take care in making assumptions about what the person wants or fighting battles for them when they are capable of doing so themselves.

3 Advocacy – what does it mean?

Activity

Think about your experiences as a carer and respond to the questions below.

- Can you remember a situation when the person for whom you are caring was discriminated against (on the basis of their age, sexuality, cultural background, disability)?

If yes, what happened? How did the person respond? How did you respond? Thinking about the situation now would you have done anything differently?

- Can you remember a situation when the person for whom you are caring had their opinions and/or wants/needs ignored by a professional (this could be a doctor, nurse, social worker etc.)?

If yes, what happened? How did the person respond? How did you respond? Thinking about the situation now would you have done anything differently?

3 Advocacy – what does it mean?

- Can you remember a situation when the person for whom you are caring could have received better service?

If yes, what happened? How did the person respond? How did you respond? Thinking about the situation now would you have done anything differently?

- Can you remember a situation when the person for whom you are caring had their right to privacy and confidentiality taken for granted? (This may mean that one of the service providers has shared information with other people without getting permission from the person concerned.)

If yes, what happened? How did the person respond? How did you respond? Thinking about the situation now would you have done anything differently?

3 Advocacy – what does it mean?

Deciding how to deal with situations of discrimination, neglect, abuse or poor service can be quite challenging.

Do we:

- wait for the person for whom we are caring to say something or to show their unhappiness? (If appropriate)
- wait until we've left the situation to talk to the person about their feelings, wants and needs in terms of further action? If they decide they do want to complain about an incident or treatment what can we do to support them?
- say something then and there?
- leave the situation and work out a way of dealing with it the next time it happens?
- lodge a formal complaint?
- contact the Carers Resource Centre or an organisation that deals with consumer rights and ask for advice?
- contact an advocacy agency - e.g. Disability Action – for advice?
- spend time researching the issue in greater depth so we have a clear idea as to what should – or could – have happened? (This may be useful in a wide range of areas – for example, housing and accommodation, medical issues, financial rights and responsibilities, respite care, individual rights etc.)
- ask the Carers Association of SA (or similar organisation) to follow up our concern or complaint?



The way we deal with an issue depends on the situation, the skills and desires of the person for whom we're caring and our own level confidence, knowledge and abilities.

4 What skills do we need for advocacy?



Earlier in this booklet we provided three short case studies where people's rights were ignored. As part of the activity we asked you to think about what you would do if you were in the carer's position. If you've been able compare your responses with other carers you may have found a range of ways people dealt with the situations.

Some people may have raised the issue with the person responsible for the poor behaviour and tried to find a solution. Others may have decided to 'fix' the problem by taking the person for whom they were caring to another doctor or another school. Although this second approach is understandable – taking this approach isn't advocating for the person concerned. If we're to advocate for the person – and ourselves – we need to take a stand. By doing this we draw upon a range of skills.

4 What skills do we need for advocacy?

Activity

You might like to read through the list below.

Tick the skills and behaviours you believe an advocate should have:

- good communication skills
- confidence
- an ability to present ideas and information in a clear, calm manner without becoming over-emotional
- an understanding of individual rights
- an understanding of what the person for whom they are caring wants
- an understanding of how they can best support the person for whom they are caring in putting forward their needs (e.g. is being there enough? Should they help role play situations? Should they find out more information so the person is clear on their position and what they should be able to expect?)
- an ability to find out information
- an ability to stick to things and not get put off by 'knock backs' or professional 'brush-offs'
- an ability to plan ahead and to think about different ways of finding out about difficult topics
- optimism and a willingness to follow things through
- persistence
- curiosity and an ability to ask questions ... and to keep asking questions until they are answered
- a knowledge and understanding of the value of 'support networks' (this may be as informal as friends and family or as formal as organised carer support groups).

It's a long list, isn't it? And it's likely that you ticked most, if not all, of these items.

4 What skills do we need for advocacy?



Now think about your own skills as an advocate. How many of these qualities do you have?

Would you believe that most carers, even the most experienced rate themselves poorly? Why? Because they believe that the skills of the successful advocate belong to ‘other people’; that they don’t have the knowledge or abilities of a professional. Fortunately, they’re wrong.

We don’t need qualifications or legal training to stand up for the people for whom we care. What we need, more than anything, is a belief in ourselves, in what we’re doing and in the rights of the individual. Once we believe these things we can then decide upon how best to advocate for the person given the situation and the skills **we** possess.

Activity

Spend a few minutes thinking about your strengths, skills and abilities. Now imagine yourself in the following situations and describe the *skills* you could/would use to advocate for the person in your care.

- a) *The Mental Health nurse who cares for your brother rarely turns up on time and never rings to let you know that he’s running late. This means that both you and your brother spend time waiting for him to arrive. Your brother finds this very distressing. The fact that the visits are becoming shorter and the worker hardly responds to your brother also worries you. It seems that your brother isn’t being viewed as an individual with his own specific needs and issues but as a ‘task’ to be completed as soon as possible.*

4 What skills do we need for advocacy?

b) A Domiciliary Care service has been helping your frail grandfather for some time and everyone has been extremely happy with the service. Over the last six months however staffing and rosters have been changed. The new worker now visiting your grandfather is very young and unable to communicate effectively as English is not your Grandfathers primary language. Her time has also been reduced. Your grandfather is very upset and has become increasingly withdrawn since the change in service.

c) You have been taking Ellen, your physically disabled daughter, to the family GP since she was born. At the age of sixteen Ellen now resents your being in the room while the doctor examines her. At the same time, though, she complains that the doctor doesn't take her concerns about muscle spasms seriously.

4 What skills do we need for advocacy?

In tackling these situations we each draw upon our own skills and abilities. And that's important. We should never feel as if there's only ONE way to advocate for others. There's not. What we do need to do, however, is to:

- think about our communication skills – a topic explored in the booklet *Communication for Carers* – and use our strengths to our best advantage
- consider what we want to achieve and how we can best approach the situation so we meet our goals
- identify agencies, support groups or individuals who may be able to give advice or assistance.

You'll find a list of useful resources and organisations that can assist you with this process at the end of this booklet.



5 The action plan



The phrase ‘action plan’ sounds fairly formal doesn’t it? It almost implies that we’re planning a battle ... and in a sense we are. There will be occasions when the person for whom we are caring will be ignored, dismissed, not taken seriously over a period of time. When this happens – we need to think carefully about the best way of dealing with the situation and then develop a plan of action.

So what do we do?

We need to:

- *involve the person for whom we care and ensure that any plan is based on what they want*
- think about the situation – e.g.:
 - what happened?
 - how often does it happen?
 - who is involved?
 - what role does each person play?
- talk about why the situation or treatment was upsetting, unprofessional or discriminatory
- think about what *should* have happened?(e.g. the person should have been seen immediately and their opinions and the information they provided should have been accepted and acknowledged rather than ignored)
- work out what options are available to best resolve the situation (e.g. do we make a formal complaint to the person involved? Do we write to the organisation? Do we ring the person’s manager? Do we compose a written record of the event, describing how the person for whom we’re caring felt about the behaviour and what they/we would like done about it – and then give this information to the service provider on our next visit?)
- seek more information or advice if necessary
- record what you consider to be the ‘best’ outcome.

5 The action plan

At this point we'll find that a number of options are open to us. To select the best and most effective we need to consider:

- our skills and abilities (what do we feel most comfortable doing?)
- the wishes and feelings of the person for whom we're providing care
- the possible outcomes of each option.

Working through an action plan isn't as hard as it looks ... in fact, it's based on common sense and forward planning.

Activity

Remember the following scenario from the beginning of this booklet?

Brenton, Jessie's 14 year old Aboriginal son, is passionate about basketball. Although he has cerebral palsy, Jessie wants him to lead as normal a life as possible. Brenton's GP has been quite supportive and has told both mother and son that playing sport would be very good for Brenton – although changes to games and rules would have to be made. The school, however, refuses to allow Brenton to play any sport stating that they would be negligent if they put Brenton and his peers at risk.

Imagine Jessie has asked you to assist her on developing an action plan. What would your plan look like?

5 The action plan

There are a number of strategies you could have used to get the best result (i.e. Brenton plays basketball with his peers). Your *final approach*, for instance, may have focused on:

- involving Brenton in developing and recording an action plan so it reflects his opinions and needs
- asking Brenton's GP to write a letter explaining Brenton's condition and his ability to play safely with others if the rules were changed to reflect his needs
- organising a meeting with the sports teacher/the school principal, Brenton's GP or a representative from a relevant health/advocacy organisation, Jessie and Brenton to discuss how the sports activities could be modified to enable him to take part
- contacting an outside organisation (such as the Carers Association or an advocacy agency) for advice about how best to handle the situation so that Brenton's needs are met.

But this is just a case scenario ... the situation, the people, the difficulties they confront are very different from our own.



5 The action plan

Activity

Spend a few minutes thinking about the person you care for and their needs. Are there areas where your support as an advocate could be of benefit to them (and to you)?

If not, that's great. If so, you might find it useful to work through the questionnaire/action plan below.

1. Briefly describe the situation.

2. Who is involved? (ie. Who is affected by the situation?)

3. How does the person you care for *feel* about the situation? How do you feel about the events you've observed and their impact on the person?

5 The action plan

4. How would the person for whom you care like to change the situation? (ie. What would they like to happen?) If they are unable to communicate their wishes, how would you like to see the situation change? What do you want to see happen?

5. List as many different ways of achieving these outcomes as you can. Then, next to each describe the advantages and disadvantages of following up each option.

5 The action plan

6. Are there people or organisations you could contact to assist you?
If so, list them below.

7. Do you need more information before you go further?
(Sometimes, for instance, we may need to find out about such things as legal entitlements or financial arrangements or the side effects of medications before we go any further.) If so, what type of information do you require and where could you go to get it?

Although everybody's situation will be different there are a number of agencies and support organisations available to assist you in advocating for yourself or someone else.

You'll find a list of useful resources and organisations that can assist you with this process at the end of this booklet.

6 Supporting others



Up until now we've largely focused on the skills we need to act as advocates for the people for whom we care ... and many of us will assume this role repeatedly in the months and years ahead. But it's essential that we don't underestimate the other person's skills, abilities and opinions. Sometimes it may appear easier – and more effective – if we stand up for the other person, but we should never assume that:

- this is what they want
- they're incapable or unwilling to advocate for themselves
- we know best.

If they decide not to stand up for themselves but are unhappy with the way they've been treated and we believe that we lack the knowledge and/or skills to take on this role, then it's important that we consider seeking outside help. But we should never take this step without first gaining the consent of the person for whom we care.

Activity

Spent a few minutes thinking about the person for whom you care ... not as someone who is dependent on you but as a person in their own right. Reflect on what they can do rather than what they can't. Consider their beliefs and values.

You may find it useful to jot down a few key words that describe their behaviour and personality below.

6 Supporting others

Now focus on:

- how they make others aware of their needs
 - what do they do?
 - what communication skills do they employ?
-
-
-

- what they do when they feel they've been ignored or discriminated against by others? (That's if they're aware that this has occurred – obviously not everyone will have this ability to discern different types of behaviour)
-
-
-

In some cases they may say what they feel. In other cases the lack of interest in their opinions may compound their sense of helplessness and further reduce their self esteem. Occasionally they may vent their frustration on us.

Now although we're not counsellors, social workers or trained mediators we possess considerable knowledge and abilities... not least of which is a good understanding of the person for whom we care. We know the person in ways that service providers don't. We recognise the changes they've gone through and the skills they're still able to draw upon. When things go wrong – when they're ignored or poorly treated – the very least we can do is to talk with them about what has happened and how they would like to respond. We don't have to take charge. It may well be enough that we listen, support and encourage.

6 Supporting others

Activity

Focus once again on the person for whom you care. What things can you do to support them in meeting their needs and standing up for their rights?

If you're unsure about how to provide support and encouragement there are a number of organisations listed at the end of this booklet who will willingly listen to your concerns and offer suggestions. Needless to say, the Carers Association is a great place to start.

The other point to keep in mind is that we don't have to do everything. If the person can't – or won't – advocate for themselves and we haven't the necessary knowledge or skills it's important that we don't feel as if we've failed. We haven't. Recognising that we're not always the best person to tackle every situation is part of recognising our strengths and weaknesses. But we need to take that knowledge a step further and seek the support of people or organisations who have the skills we lack. Again, the listing of contacts at the end of this unit is a valuable place to start.



7 Advocacy and confidentiality: recognising when it's not okay to tell



Confidentiality is something most of us treasure a great deal. Unfortunately we don't always recognise that fact until it's been breached – a friend or service provider, for instance, may have shared personal/private information with other people without our permission. When that happens we often feel betrayed. In some cases, it can have a big impact on our employment, our social life, our relationships and our friendship networks.

Activity

Spend a few minutes reflecting on the things about yourself you share with others. You may like to consider such areas as:

- your beliefs
- your personal history
- your sexuality
- your finances
- your medical background
- the relationships you've had over time
- any contact you've had with the police or the legal profession.

All of us have things in our past – and often in our present – that we choose to keep private. We believe, rightly, that these things are *our* business ... that they have nothing to do with our work colleagues, our friends, perhaps even our partners and families.

The person for whom we care probably feels the same way about their privacy ... in their case, however, they have less control over what other people know about them. We, for instance, learn a great deal through the act of caring. Similarly the various social workers, nurses, doctors, domiciliary care workers, financial advisers, volunteers with whom they come into contact learn things about them (and us!) that under 'normal' circumstances they would never know.

7 Advocacy and confidentiality: recognising when it's not okay to tell

As we mentioned earlier, many organisations and agencies have policies and procedures relating to how they operate – policies that often include handling complaints and maintaining confidentiality. One thing we can do is to ask service providers about these policies. How, for instance, will they use the information we provide? At this point it's important to mention that we can (and should) insist that the we – and the person for whom we care – must be consulted before personal details are shared with other professionals or workers.



As the person's carer, it's important that we too respect their privacy and that when giving information we do so with their permission. (Although doing this isn't always easy, especially when the person is non verbal, has dementia or experiences a mental illness episode). Situations may arise when there is a conflict between our rights and needs and those of the other person. You may find the booklets *Rights and Responsibilities for Carers* and *Communication for Carers* useful resources in dealing with these issues.

Activity

Consider your own caring situation. What information do you consider safe to tell? What information would you keep to yourself?

7 Advocacy and confidentiality: recognising when it's not okay to tell

The question of sharing information/maintaining confidentiality can be quite complex. Do we tell the doctor that the person for whom we care has had two blackouts recently when they've insisted that they don't want anyone to know? Do we tell the support agency that the worker they've provided isn't doing her job properly? (Even though the person for whom we care has asked us not to say anything because they don't want the worker to get in trouble?)



Again, it's important to remember that we're not alone. If we learn facts of a private nature that worry us or we're not sure how to handle a certain situation we need to contact a supportive organisation (such as the Carers Association) for advice. Needless to say we can do so anonymously so we're not breaching the person's confidence.

But - we're not the only people with access to information about the person for whom we care. Service providers can also discover a great deal about the person, their living situation, their families/friends and the person's past activities.

Activity

Consider how the person for whom you care may feel if their confidentiality had been breached by a service provider. What impact might it have upon them? What impact might it have upon you?

7 Advocacy and confidentiality: recognising when it's not okay to tell

What steps would you take if you found out that a service provider had breached confidentiality and that the breach affected you and members of your family?

Breaches of confidentiality can occur for a wide range of reasons. People may simply be:

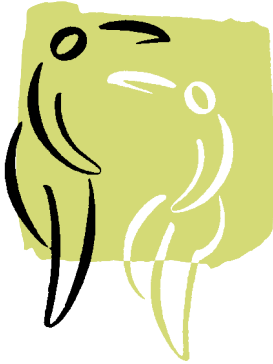
- involved in gossip or a casual conversation ('Guess what happened at work today? Well I went to old Mr Smith's and')
- behaving in a thoughtless manner
- sharing information with other service providers because they believe the other person 'should know'.

Reasons for the breach are unimportant ... it's the impact we need to think about ... and our response to that breach.

Issues around confidentiality can be complex and confusing. But they can be worked out if we take time to talk through issues and concerns with the person for whom we care and the relevant service provider. Effective communication (and you may like to refer to the booklet *Communication for Carers*) is important when talking about and clarifying issues relating to confidentiality.

8 Conclusion

Advocating for ourselves and others isn't always easy – however – sometimes it's not as difficult as we think it might be.



We need to understand our rights as individuals and consumers. We need to recognise that people deserve to be treated fairly, equally and with respect and regard. Once we're clear about these expectations we can look at how best to deal with situations when we are unhappy with a treatment or outcome. To do so involves discussing options with the person for whom we care, identifying what we want to achieve and then drawing upon our own knowledge, skills and abilities to pursue that particular goal. Sometimes we'll need to research matters. At other times we may need to seek help from others. That's fine. In fact, being able to recognise resources and to tap into the most appropriate support agencies/mechanisms/individuals lies at the heart of effective advocacy.

As individuals who have spent months or years caring for others, we have a wealth of skills and experiences to draw upon. We should never allow others to dismiss our experience. As carers our knowledge and experiences can be used to improve the lives of those around us. Advocacy – be it formal or informal – is one very effective way in which we can do so.

9 Resource listing

Useful resources

Information on Caring

- Carers Association of SA

Available from

1800 815 549
08 8271 6288

-
- Carer Information Kit

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*

General information on rights

- Your Rights and Responsibilities –

A charter for South Australian Public
Health System Consumers

1800 242 636 *Carer Resource Centre*

-
- Aged Rights Advocacy Service publications

Participation in Decision Making
Getting it Right

1800 700 600 *Aged Rights
Advocacy Service*

On advocacy

- Introduction to Advocacy

- Advocacy and Indigenous People in Australia 1800 805 495 *Disability Action*

- Advocacy and Older People 08 8346 8288 *Disability Action*

- Advocacy and People with a Disability

- The Kit – a guide to the advocacy that we
choose to do (a resource kit for consumers
of mental health services and family carers)

02 6285 3100 *Mental Health Council
of Australia*

9 Resource listing

Organisations

For information on advocacy and assistance

- **Carers Association of SA** 1800 815 549 www.carers-sa.asn.au
 - **Carer Resource Centre** 1800 242 636 *Carer Resource Centre*
 - **Carer Support Groups** (Carer Resource Centre can refer you to your local group)
 - **Your local Carer Support group** (Carer Resource Centre can refer your local group)
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- **Aged Rights Advocacy Service** 1800 700 600
08 8232 5377
-
- **Citizen Advocacy SA** 08 8410 6644
-
- **Disability Action** 1800 805 495
08 8346 8288
www.disabilityaction.asn.au
-
- **Disability Complaints Service** 1800 088 325
08 8234 5699 www.dcs.sa.com.au
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- **Ethnic Link Services** 1800 648 598
08 8241 0201
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- **Mental Health Council of Australia** 02 6285 3100
-
- **Mental Health Resource Centre** 08 8221 5166
-
- **Migrant Resource Centre** 08 8271 9500
-
- **Nunkuwarrin Yunti of SA** (advice and advocacy for Aboriginal people) 08 8223 5217
-
- **Office of Public Advocate** 1800 066 969 www.opa.sa.gov.au

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.

10 Evaluation **Advocacy for Carers**

You have now got to the end of the support materials to develop your skills in 'Advocacy'.

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.

