

Advocare NEWS

Volume 7, Issue 2

June 2003

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INDIVIDUAL CHOICES OR PREFERENCES – TAKEN SERIOUSLY?

When residents or family members contact Advocare over varying issues there are often a few frequently raised questions that they ask and these are often framed within a mood of doubt and uncertainty. These questions are often put to us in the following way:

‘Am I being reasonable or am I being unrealistic?’

‘I thought personal choice was a priority but apparently the facility has a policy which doesn’t allow this.’

‘I’ve been told that this is not allowed because of their ‘duty of care’.

In most cases our experience is that the resident or family is not being unreasonable at all and what has happened is merely a breakdown in communication and understanding.

If residents are to feel valued and included then their individual preferences and choices need to be explored and appreciated. Initially this may take time and we are aware of some of the pressures that staff face which may result in this not happening. It is also common for residents, or families, to find the process of articulating what it is they expect and want from the facility a difficult one.

The result can be that much remains unstated or left unclear and if this continues then all parties may not have a very satisfying experience within the facility and issues eventually emerge with no apparent cause.

Staff attempt to encourage feedback regarding care and service delivery through such avenues as comment forms, an open door policy, etc. It is unfortunate that residents often perceive these avenues as a complaint rather than feedback to improve things in line with a commitment to continuous improvement.

Advocare’s approach is an acceptance of those individual preferences and an exploration of what is possible given the limitations that the facility has in delivering a service.

When this is undertaken in a spirit of ‘good faith’ and genuine regard, all parties tend to relax and be receptive to what is possible. If ‘duty of care’ or organisation policies are used in such a way that residents are thwarted or disempowered in this process we arrive back at a sense of doubt, uncertainty and dissatisfaction.

We believe (and it is our experience) that most issues are able to be resolved. By focusing on ‘rights and responsibilities’ throughout our dialogues with staff and residents there is often a gradual shift from a sense of frustration and disquiet to one of resolving issues, with confidence in the results.

Stephen Evans



Please feel free to photocopy this newsletter as often as you like,
and distribute it to clients, residents, carers, staff and visitors!

HOW GOOD ARE YOU AT COMPLAINING?

The purpose of complaining should always be about quality care and services. It is an opportunity for clients and service providers to review standards, to consider best practice and innovation, to enhance quality of life and to continuously improve. A well-presented and handled complaint can stand as the keystone in client/ service provider relations.

Complaining involves communicating your needs to others for the purpose of engaging their assistance to resolve a problem. My test of a good complainer is how quickly he or she gets a solution that is satisfactory to everyone involved.

Residents and HACC clients all have a right to complain. Facilities and HACC service providers are required to have complaint handling forms and procedures and to make them available to clients. Service providers are required to deal with complaints fairly, promptly, confidentially and without retribution.

Here are some suggestions and ideas to make your complaint work for you.

1. Its usually better to deal with problems as they happen and not let them build up.
2. Understand the nature and scope of your problem. Assess the problem in terms of importance and urgency. If it is important then it



maybe useful to write it down on paper including; all the facts that you know about the problem, try to identify specific issues and write them in the form of separate questions then write what it is that you want to achieve. Try and focus on issues and not personalities. If you have a problem with a person try and identify what that person did or said that annoyed you. Ask yourself if what you have written looks reasonable? If you need more information, take action to obtain it. Identify your time frame for resolution. Identify all the people who are effected by the problem. The clearer you are about the problem the better the outcome will be.

3. Talk about your concern with others. If it is a simple matter and you know who can fix it then talk to them directly. If it is important and worrying you can speak confidentially with our staff. Talk to family, friends or carers. Sometimes just talking fixes things. Mention

it at the next Residents and Relatives meeting. Others may share the concern and support you in raising it. Our staff are able to provide support.

4. If the problem is either not urgent or not very important you may wish to complete a complaint/suggestion/quality improvement form or book entry provided by the service provider. If you require a response then let people know and fix a time frame.
5. If the problem is important and/or urgent you should discuss it with others and make an appointment to talk to the person responsible for dealing with complaints for your service provider.
6. When dealing with problems you must regularly assess the impact the problem is having on your own health and emotions. If you think the process of pursuing a complaint may be taxing on you then ask others for support including our office.
- 7 Tell your service provider the following as a minimum: the facts, the problem, how the problem effects you, what you want to achieve and your time frame. Giving this in written form provides a clear agenda and record for the meeting. The task is then to discuss and negotiate a solution. Be

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SELF CARE

In the caring professions carers are often the first people to forget about their own needs, focusing more on assisting their clients.

What, then, is so important about “self care”? Self care is important to the point that it enables us to continue in paid employment, provide support to our families, enjoyment in what we do, retain our sense of humour, think positively, take part in outside activities, develop personal support systems and the like. Without exercising self care we run the risk of becoming disinterested in our paid work, feelings of isolating from colleagues, lacking in positive response to those we love, bored, lonely, experiencing self-defeating thoughts, unable to relax, or generally enjoy life.

How do we implement self care? Communication is the basis for

developing strategies to overcome problems. Sometimes difficulties arise in the workplace, and instead of dealing with them immediately, we hold on to the hurt or dissatisfaction that has occurred. It may be that one of your colleagues has spoken to you in a rude or intrusive manner but that you have been too busy to deal with it, or too offended to make a rebuttal. However, before you leave the work site for the day – deal with the issue. The fact that it may take 10 to 15 minutes is a lot better than taking that hurt home to your family and letting the problem impact on your relationships. It may be that you lose sleep because you are worrying about how you’re going to approach that person the next day. Don’t let problems eat away at you.

Sometimes we feel overloaded with our work and can find

ourselves feeling tired, stressed, and impatient. Take a few minutes to organise yourself by prioritising your tasks. If the situation continues, it may be that you need to speak with your supervisor to develop some changes that will assist you to complete the tasks. It may be that a reorganisation of duties with other staff occurs to overcome problems that others are also experiencing.

Remember, before you can help others, you have to be able to look after yourself. Prioritise some time regularly for yourself to enjoy and don’t ever consider that you are the only person who can do that allotted task. If you are not there tomorrow the job will still be done, maybe not as you would do it, but there’s always someone else who will do it!

Margaret Cowan-Guthrie

To the world you might be one person, but to one person you might be the world.

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prepared to listen to the views of others. Stay committed to resolving the matter and ask the same of others. If you want support in speaking with your service provider ask if you can have a friend present or telephone our office. Depending on the nature of the problem it may take several meetings

with different people to resolve. Keep a record of events. If you manage to reach an agreement ask to have it clearly recorded in writing to avoid any subsequent confusion and fix a date to review and check if the solution is working.

8. If the matter is still not resolved to your satisfaction you can discuss (with Advo-

care or others) employing other more formal means of resolution.

Regardless of the outcome, a properly handled complaint should foster client respect and trust as well as being a valuable feedback mechanism for the service. It is up to all of us to make it a ‘win-win’ experience for each of us.

Michael Crowley

MULTICULTURAL LINKS THROUGH THE USE OF DAY CENTRE TEMPORARY INTERPRETERS

The Abuse Prevention Program (APP) at Advocare has maintained an ongoing commitment to the development of providing education to various cultures in and around Perth. Of late, the APP has begun to focus more closely on providing this education to multicultural groups as the demand for it is steadily increasing. This increase has coincided with more cases of elder abuse within various cultural settings being brought to the attention of the APP where the older adult is not able to communicate directly with us, being that in many cases English is not their first language.

It has always been a policy of the APP to become more specialised in the delivery of education to ethnic groups in a way that is geared towards cultural sensitivity and an understanding of their needs.

So far we have begun to work with multicultural groups through a series of talks at a multicultural day centre. The talks have been given to various cultural groups including the Italian and Greek community and Macedonian and Cantonese older adults. Community groups such as a day centre can provide access to individuals and can serve as a forum for participation.

What has had considerable success as a result of these presentations is that we have been supported by carers from the day centre who act temporarily in the role of interpreter. As the temporary interpreter is themselves of the ethnic origin of the older adults, they can deliver the information almost instinctively, knowing what formula will be most effective for the target audience of that particular day. Our agency needed to recognise the varied style of communication derived from ethnic or minority cultures and these temporary interpreters where able to express this as language difficulties are often the most immediate hurdle to overcome in order to work effectively with various cultural groups. As a result the interpreters have become the backbone to the success of the presentations thus far, becoming almost like our own 'inside trader'.

Another key highlight of the use of the temporary interpreter is in connection with the already established relationships that they have formed with many of the older adults who frequent the day centre. This established rapport with the older audience often coupled with having knowledge of the older adult's family dynamics, puts the temporary interpreter in a

position of trust. This can often be a key element to the success of dealing with such a delicate subject such as elder abuse.

The day centre's temporary interpreter can also help to refer the client to our program if they are in a situation of abuse as they have volunteered to extend their role of interpreter outside of their centre. This has helped to decrease the resistance of many older adults who are often afraid of the consequence of disclosing their abuse as they feel a genuine assurance that their issues will be treated as confidential.

The success of the day centre temporary interpreter warrants our sincere gratitude to those who have fulfilled this role so far. As a result of these initial presentations we have also had inquires for more talks from other multicultural centres around Perth. The APP would also like to mention that we provide education to other older adults where English is their first language, service providers, students, government institutions and other relevant agencies. Our education is free of charge.

Claudia Ferrante

ACCESS TO INFORMATION IN FACILITIES

This article is to inform residents of their right to access information pertaining to them. It is also to advise aged care facilities of their legal obligations regarding residents and their representative's right to access information.

Throughout this article, I will be drawing directly from the *Aged Care Act 1997*, the *Privacy Act 1988* (as amended on 21st December 2001), *Guidelines To The National Privacy Principles* (which was published by the Office of the Federal Privacy Commissioner in September 2001), and *Guidelines On Privacy In The Private Health Sector* (which was published by the Office of the Federal Privacy Commissioner on 9th September 2001).

The *Privacy Act* generally applies to aged care facilities. In Schedules 3 6.1 of the *National Privacy Principles* it clearly defines a resident's right to have access to information about them held by an aged care facility:

“if an organisation holds personal information about an individual, it must provide the individual with access to the information on request by the individual”

There are eleven exceptions to this rule as outlined in Schedule 3 6.1 (a – k). One example being, if this access would pose a serious threat to the resident. Further to this (as stated in 6.7 of Schedules 3)

“an organisation must provide reasons for denial of access or a refusal to correct personal information”

Decisions to deny or refuse access can be referred to the Privacy Commissioner for review.

In the circumstances where an individual does not have physical or mental capacity (as stated in Schedule 3, Clause 2, 2.4 of the *National Privacy Principles*):

“an organisation that provides a health service to an individual may disclose health information about the individual to a person who is responsible for the individual if:

(a) the individual:

- (1) is physically or legally incapable of giving consent to the disclosure; or
- (2) physically cannot communicate consent to the disclosure;”

Therefore when a resident has another person representing their interests – that person (according to Schedule 3 Clause 2, 2.5 of the *National Privacy Principles*) has a right to access information on behalf of the person they are representing if they are either:

- “(a) a parent of the individual; or
- (b) a child or sibling of the individual and at least 18 years old; or
- (c) a spouse or de facto of the individual; or
- (d) a relative of the

- individual, at least 18 years old and a member of the individual's household; or
- (e) a guardian of the individual; or
- (f) exercising an enduring power of attorney granted by the individual that is exercisable in relation to decisions about the individual's health; or
- (g) a person who has an intimate personal relationship with the individual; or
- (h) a person nominated by the individual to be contacted in case of emergency”

Coupled with this, the *Aged Care Act* states (in the *Quality of Care Principles 1997* under the heading of “Principle” in Schedule 4, Part 5):

“The dignity and privacy of each care recipient are to be respected, and each care recipient (or his or her representative) will have access to his or her personal information held by the approved provider”

A “care recipient” is defined in 18.4 (1) in the *Quality of Care Principles 1997*:

“care recipient includes prospective care recipients and residents”

The term “care recipient representative” is defined at in 18.4 (2) of the *Quality of Care Principles 1997*:

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“Examples of representative:

1. Advocate
2. Carer
3. Legal guardian
4. Relative”

Now that I have outlined the rights of residents and their representatives in relation to gaining access to information pertaining to residents, I will define “access”. According to the Guidelines on Privacy in the Private Health Sector, under the heading “A.6 Key Concepts”,

access has the following meaning:

“Access – this involves a health service provider giving an individual information about themselves. Access may include inspecting personal information or having a copy of it”

In concluding this article, I would urge that residential aged care facilities in setting your policy to follow these legislative guidelines in allowing residents and their representatives (which as previously stated includes

advocates) access to information pertaining to them. I can't emphasise enough how difficult it is to resolve a residents complaint with a facility when the facility refuses to allow a resident or their representative access to information relevant to the complaint. Apart from the possibility of breaching both the *Privacy Act* and *Aged Care Act*, this does nothing but hinder the advocacy and complaints resolution process.

Krystal Holmes

FORMAL AND INFORMAL ADVOCACY FOR VICTIMS OF ELDER ABUSE

Westhorp and Sebastian (1997) explain that professional and other types of formal advocacy is “provided by a worker who is paid to advocate on behalf of others” (p. 21). Examples of formal (or professional advocacy) include lawyers, unions and advocacy services, such as *Advocare*. Formal advocacy may also be available, for example, from community services, social institutions, religious organisations, and educational institutions.

Professional advocacy for victims of elder abuse is based on the view that the most effective way to involve seniors in resolving personal abusive situations is by supporting them to regain control. Health Canada (1994) reported that keys to successful empowerment include:

- “Receiving and understanding information on one's rights

and what constitutes abuse;

- Understanding all possible choices and their consequences;
- Having one's privacy, dignity and right to risk respected;
- Being offered continual support through the process; and
- Receiving support and respect for the ultimate decision and subsequent action.” (p. 14)

Health Canada (1994) further asserts that “The challenge for seniors and professionals involved in the issue lies in creating an environment where an older person feels confident to speak out about abuse and ask for help in both practical and emotional terms.” (p. 14)

With regard to skilled formal advocates the PEAT (Prevention of Elder Abuse Task) Force (2001) specifically assert that, “informed intermediaries are

particularly important for groups who may experience difficulties in accessing mainstream service and information ... such groups include people from culturally diverse backgrounds, people from rural areas, and people with high levels of disability.” (p. 18)

With general regard to support for victims of elder abuse Baron, Burns and Suls (1988) also explain that there are many kinds of social support that can assist someone to deal with “social pressure”, some being more effective than others. Furthermore, support that is attained earlier on in the situation can be much more beneficial than that which is available once the victim has succumbed to the pressure and control. (p. 166)

Bethany Faye

(Please see back page for references)

CARER STRESS

In Advocare's Speak Out Survey on Elder Abuse, a respondent reflected on how difficult her caring role was, stating:

My mother has dementia and I can see how a carer could abuse.....She has two daughters and one son. I (a daughter) have it all on my shoulders. I also see where a lot of folk come from.....I can understand why some abuse older people but I never would.....I understand why carers are put in a position of abusing an older person. I'm afraid I will do that. (Note: This lady was extremely distressed when she called) (bf8)

Carer stress is a reality for many who care for the frail aged, yet, according to the Aged Rights Advocacy Service (2001) it constitutes less than 10% of risk factors for abuse. Analysis of the Speak Out Survey data has also revealed that carer stress is less of a risk factor in relation to elder abuse than has previously been theorised. Such arguments, according to Pillemer (1993), see elder abuse as a "natural outgrowth of the aging process that leads to the need for family care" (p.239). Steinmetz (cited in Pillemer, 1993) asserts that, as parents grow older, families may undergo 'generational inversion', in which the older adult becomes dependent upon his or her children, placing the caregiver under severe stress.

These views imply that older adults become a burden upon their families, and as such are responsible for the abuse. However, as McDonald and Collins (2000) assert:

One major flaw of this

perspective is that it fails to account for the fact that some caregivers, who experience the same stresses as abusers, do not abuse their elderly. The perspective has also been criticised for being dangerously close to blaming the victim, because it identifies the older person as the source of abuse (p.28).

As such there is a danger of relieving the alleged perpetrator of responsibility for his/her abusive behaviour. When such behaviour is attributed to carer stress, it is possible that the existing power imbalance is perpetuated. While the alleged perpetrator may receive support, the alleged victim could be left further exposed to exploitation and abuse.

James and Graycar (2000) assert that, where carer stress is associated with elder abuse, it is usually accompanied by factors including dependency, on the part of the victim, and/or substance abuse or psychiatric illness on the part of the perpetrator. Furthermore, according to Pillemer (1993), a perpetrator of abuse may also be dependent on the victim, particularly financially dependent. These assertions have been supported by the Speak Out Survey, in which around 20% of alleged perpetrators were under financial stress, and many older adults reported adult children 'freeloading', living with their parents and not contributing to the household costs.

According to James (1994) not everyone is suited to provide

care for their elderly parents or relatives, with family members who are not economically, psychologically, or physically prepared to take on the responsibilities of the commitment of caring being more likely to be abusive (p.96). In addition to this, as Janzen and Harris (1986) state, one major factor that predisposes carers to be abusive is having a history of long-standing conflict with their parent. These authors also emphasise that "where conflict is unresolved, aged parents and their children will not be able to live comfortably together" (p.163), and as such a 'caring role' would be considered inappropriate.

Although she expressed her fears about the possibility that she could abuse her dependent mother, the above quoted survey respondent emphasised a number of times that, to date, she had not hurt her mother. Most carers have positive relationships with their parents and are less likely to be abusive. It is likely this was the case for this carer. However she did acknowledge the difficulty of the caring role and was clearly distressed, and was consequently referred by the researcher to appropriate counselling and carer support. Such support does exist through agencies such as Carers WA and Alzheimer's Australia WA Ltd, and is crucial in the prevention of elder abuse.

Maureen Sellick

(Please see back page for references)

REGIONAL VISITS

Advocates from our office will be making visits to Albany, Geraldton and locations in the Heartlands and South West over the next six weeks. This is part of our annual pilgrimage to these and other regional areas. Further visits are being planned for Kalgoorlie and the Kimberley region later in the year. On these visits advocates from our office plan to meet with residents and staff at aged care facilities and also HACC clients and service providers.

The visit details are as follows:

Geraldton area visit by Miriam Kelly on the week beginning 9 June 2003.

Augusta, Northcliffe, Pemberton, Manjumup and Nannup being visited by Krystal Holmes over the week beginning 9 June 2003.

Northam, York, Beverley, Quairading, Bruce Rock, Merredin, Brookton, Pingelly, Narrogin, Wagin, Corrigin and Kellerberrin being visited by Michael Crowley during the week beginning 30 June 2003.

Albany, Denmark, Mount Barker region visit by Stephen Evans on the week beginning 14 July 2003.

If you are in these areas and wish to be included in meetings with our advocates please feel free to ring our Perth office on 9221 8599 or 1800 700 600 (for country callers).

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Advocare assists and supports you to exercise your rights as consumers or potential consumers of residential care and community care services.

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www.iinet.net.au/~advocare

Advocare is funded by:



Commonwealth Department of Health and Ageing



Health Department of Western Australia