

Think Patient – Think Carer

Supporting and involving carers

A guide for general practitioners and primary care teams



Health
Northern Sydney
Local Health District

www.nscarersupport.com.au

Supporting carers in our community

A significant number of people in our community have a disability, mental illness, are frail aged or have a chronic condition that requires unpaid care and support from a family member or friend. We refer to that person as a *carer*.

Carers are a recognised group who have an important role to play in our health care system. They support the patient in their journey: in communicating, participating in health decisions and in looking after the patient's health and wellbeing at home.

Carers can often neglect their own health and in many cases it's only a matter of time before they become sick. As a health professional, it's important you can identify a carer and provide them with the much needed help and support they deserve.

This guide aims to provide information to general practitioners (GP's) on the caring experience: what it means to be a carer, the impact of caring for another person as well as how a GP can support those important partnerships in caring.

We value the role of GPs in supporting the carer to care as well as helping them to look after themselves and pointing them in the direction of appropriate support where necessary.

We acknowledge and thank the Princes Trust, UK for enabling us to inform our development of this guide, which based on their work, is adapted for GPs in New South Wales.

Thank you for supporting the carer of your patients.

Barbara Lewis

Manager, Carer Support Service

Northern Sydney Local Health District

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Think patient – Think carer

Tips to support carers

✓ **Just listen!**

Carers look to GPs and other members of the Primary Care Team for support both for themselves and the people they care for.

Carer knowledge and co-operation about the person being cared for are vital for planning and implementing any care plan successfully. Engaging and co-operating with carers is an essential part of good patient care.

✓ **Think carer health & wellbeing**

Carers often neglect their health and wellbeing. Up to 40 per cent experience psychological distress or depression.

✓ **Identify a carer**

Recognise your patients who are frail aged, have a mental illness, disability or chronic condition. Identify their family carer and seek to include them in appointments and medical decisions.

✓ **Plan for emergencies**

Carers are affected when it comes to unexpected emergency situations. Have an emergency plan in place that covers patient information in case of hospitalisation and outlines who cares for the patient if the carer is hospitalised.

✓ **Hospitalisation – tell us**

If patient is to be hospitalised and there are cognitive impairment difficulties ensure you alert the hospital. Contacting Carer Support NSLHD can facilitate a calm journey.

✓ **Link to Carer Support**

Ensure the carer is aware of the social, emotional, financial and physical support available through the government, psychologists, general practitioners and other formal and informal support networks.

Carers NSW – 1800 242 636

NSLHD Carer Support – 9462 9488

www.nscarersupport.com.au

1. Carers - the quiet achievers

It is estimated that one in ten patients on any general practice list is a carer, although many go unrecognised.

Primary care is often the initial point of access for carers with many identifying they consider their General Practitioner (GP) the right person to point them in the direction of support and services.

Carers provide extremely valuable support to the people they look after. They allow your patients to maintain their independence, wellness and quality of life.

As a society, we do not have the financial resources to provide this level of individual support without carers.

Therefore, keeping carers well is critical, because they can experience a range of negative health, social and financial consequences as a result of their caring role.

It is important that primary care providers are aware of the range of issues that carers may face, and that GP's are able to identify carers, involve them in patient care where appropriate, support them to maintain the caregiving situation and monitor their health and wellbeing.

The NSW Carers Recognition Act 2010 defines a carer as a family member, partner or friend who provides care and support to a person with a disability, a medical condition (including terminal or chronic illness) a mental illness or is frail and aged.

Carers provide:

- ✓ General care and nursing tasks such as giving medication, changing dressings, helping with mobility and monitoring the health and wellbeing of the care recipient.
- ✓ Intimate care, including hygiene, toileting needs and dressing
- ✓ Meal support
- ✓ Emotional support and supervision.
- ✓ Domestic tasks such as shopping, cleaning, gardening, washing and ironing.
- ✓ Child care when parents are ill and unable to care for their children.
- ✓ Other tasks, such as bill paying, entertainment, support to appointments and translating.

2. Identification of carers

Although carers do not generally choose to be carers, most prefer to look after their family members or friends themselves rather than have someone else care for them.

It is a role that may come suddenly and unexpectedly, for example after injury or sudden illness. Alternatively the carer's role may creep up over time if the person has a progressive illness. Thousands of people move in and out of caring roles every year.

It is important to recognise that some carers do not regard themselves as a carer, or may dislike the label *carer* believing it can detract from their identity as a parent, child, partner or sibling to the person they care for.

It is also important not to confuse carers with paid care workers, who we refer to as Community or Aged Care workers.

Case Illustrations

The following are stories that reflect the diversity of carers you might see in your practice:

- **Mohammed** is 22 and lives with his mum who has schizophrenia. She is currently going through a bad patch, his father passed away a few years ago.
- **Burt** is 84 and is looking after his wife who has dementia and a chronic medical condition.
- **Julie** is 36, a single, working mum and her father has cancer. He is a widower so Julie is trying to juggle work, looking after her daughter and provide practical and emotional support for her father who lives over 100 kilometers away.
- **Amy** is 14. Her mother has multiple sclerosis. Her father has given up work to look after her mother, but relies on Amy to give him a break and help out when she comes home from school.
- **Pavel** is 62. He has rheumatoid arthritis. His wife has just been discharged home from hospital following a stroke.

Tips for identifying carers

- ✓ It is important to note who the carer is, this can be done through:
- ✓ Registration forms. Include a question on your registration form that asks "Do you rely on someone for your care? Does someone rely on you for their care?"
- ✓ Self-identification. Carers may also identify their role to the GP or it may come up in conversation.

- ✓ At diagnosis or first appointment. This is a good opportunity to find out who will be providing most of the care and support for patients who have longer term illness/disability.

Young Carers

Young carers are people under the age of 25 who have caring and support responsibilities for a family member with a disability, chronic or mental illness, is frail aged or has a problematic use of alcohol or other drugs.

The young person might help care for a parent, grandparent, a sibling or more than one person in their family. Young carers can be found in many different family situations, from intact family units, to single parent households and/or living with their grandparents or extended families. They can come from all socio-economic groups and cultural backgrounds.

There may be circumstances where a patient is being cared for at home by a child, adolescent or young adult. It is known that children as young as six have provided care and support to a family member.

Young Carers can be supported by:

- ✓ Having age appropriate information about the health issues and care requirements of their family member. Knowing what the issues are helps younger people cope better.
- ✓ Being included in and advised of decisions that will affect them in some way.
- ✓ Having a supportive network which includes friends and extended family. People they can trust and share responsibilities with.
- ✓ Ensuring they have time for themselves. The needs of young carers can often be overlooked especially at intense times.
- ✓ Helping them with a plan in the event of hospitalisation or crisis can be very helpful.
- ✓ Referral to the Carer Support Service to access specific support for young people.

A Young Carer brochure is available for your practice to make available for patients

Tips for Identifying Younger Carers

Specific questions may be required to ascertain arrangements where younger carers may be involved:

- Who helps to care for the patient at home?
- What effect do the condition and personal care needs of the person requiring care have on the family?
- Is there a child/young person in the family who helps provide care? If so, which tasks does he/she do?
- How does this affect the child/young person physically, emotionally or educationally?

Carers from culturally & linguistically diverse communities (CALD)

Carers from culturally and linguistically diverse communities may be harder to reach and require an acknowledgement and awareness of social, cultural and linguistic backgrounds.

Seeking support from and engagement with the wider CALD community groups and Statewide Multicultural Health Services may help to develop an understanding of how to approach and provide culturally appropriate services to your CALD clients.

CALD carers may not readily identify with being a carer or understand the concept of the term 'carer' as caring for family members can be a strong part of the culture.

CALD carers may face additional barriers to other carers such as:

- Language and communication difficulties
- Lack of knowledge and understanding of the mainstream health care system and services.
- Lack of competence of the health care system in responding to the needs of carers from CALD backgrounds.

When communicating with patients and their carers who are not fluent in English, you can help provide a culturally appropriate and equitable service by accessing professional interpreters through the Translating and Interpreting Service (TIS).

Medical practitioners (GPs) are eligible to use the TIS in their private practice through the Doctors Priority Line (DPL) when providing services to CALD patients with Medicare who are Australian citizens or permanent residents.

Medical practitioners who meet these criteria can register for access to **free TIS** services by completing the [register for a TIS National client code \(Agencies/Forms-for-agencies/Register-for-a-TIS-National-client-code\) form](#). If you need assistance in completing the client registration form for free services, please call TIS National Language policy liaison team on 1300 575 847.

3. Carers as Partners in Care

Carers know the people they care for better than anyone.

Their knowledge is extremely useful in planning patient care and in the identification of problems that require intervention.

When care is planned without the input of carers, research has shown that outcomes for the patient include more frequent hospital admissions, poor medication management and a lack of integration of care.

Engagement and co-operation with carers is an essential part of good patient care.

Co-operation may be needed from carers to effectively implement a patient care plan. Involving carers and listening to their views when devising a care plan is likely to result in much better co-operation and agreement.

Tips for incorporating carers in care treatment and planning

- ✓ Explore the ideas, concerns and expectations of carers and other family members.
- ✓ Adopt a problem based approach with carers to clarify clinical and non- clinical issues that need to be addressed. Identify priorities by using skills in problem identification, exploration, prioritisation, negotiation and shared decision-making.
- ✓ Develop your ability to use the medical records and information tools to enhance and inform the shared decision-making with patients, carers and multi-disciplinary teams.
- ✓ Actively involving carers in the planning and implementation of long-term management plans of those they care for, particularly when developing Advance Care Directives and discussing aspects of health Advance Care planning.
- ✓ Develop holistic and shared decision-making approaches to treatment plans with patients and carers. Co-develop plans which incorporate an appropriate range of standard clinical and, where safe and effective, keep with patient preferences and complementary approaches to treatment.
- ✓ Co-ordinate and integrate the agendas of carers and other family members with that of the patient and your own agenda. Enable shared decision-making and agree on management plans.

Appreciating carers may need different information and support depending on where they are on their caregiving journey, consider providing or signposting them to carer education materials, specialised advice or training for specific aspects of their role (e.g. advice about lifting and transferring a patient).

Carer support groups and information on carer education is available on the Northern Sydney Local Health District Carer Support website www.nscarersupport.com.au or you contact the service on 9462 9488.

Sharing Information

Respect for privacy and confidentiality as well as the self determination of patients is critical, however there may be some circumstances where you decide there may be a benefit in involving a carer in information sharing and treatment decisions. In such circumstances:

- Talk to patients routinely about the issues surrounding information-sharing and seek their permission for appropriate information about their care and treatment to be shared with their carer.
- When planning patient care, where possible ask carers first about any problems they may be having and their views about the best course of action to support the patient.
- Where a patient is reluctant for all information to be shared, talk through the consequences of this decision; there may be some aspects of their condition they are comfortable to share.

- Where a patient does not want any information given to their carer, ensure there is general information on relevant health conditions available, for example leaflets on medical conditions or the effects of medication.
- Introduce agreements on information sharing and record them prominently in the patient's notes so other members of the team are aware of them.
- Ask the carer to feedback any difficulties encountered once a new care plan has been instituted.

Carers of people with a mental illness have the right to:

- Define limits with regard to their availability to their relative or friend, and have these limits respected.
- Have their concerns about their relative or friend heard and acknowledged.
- Act as an advocate, in consultation with their relative or friend, to ensure that their rights are upheld.
- Under the **NSW Mental Health Act 2007**, participate in the assessment, planning and delivery of care for their friend or relative, including discharge from an inpatient unit.

Carers of people with a mental illness have the responsibility to:

- Provide timely and relevant information about the person living with mental illness to assist clinicians to provide the most appropriate assessment, treatment and support.
- Consider the opinions of professional staff regarding the treatment and care of the patient.
- With the patient's consent, consider participating with health professionals in implementing a care plan.

In some cases, patients lack the mental capacity to make a decision about sharing their personal information with carers. A person should be able to:

- Understand the information relevant to the decision
- Retain that information long enough to make a decision
- Use or weigh that information as part of the process of making that decision
- Communicate his or her decision using verbal or non- verbal communication.

If this is not possible and you need consent for treatment or a decision around disclosure of information you may need to turn to the person responsible or guardian. The carer may also hold these roles and functions, but not automatically, so you need to check.

4. Carers as decision makers

Person Responsible and Guardian

The person responsible is a position recognised and defined under Part 5 of the NSW Guardianship Act. It is the person legally able to provide substitute consent if required and under certain circumstances.

The NSW Trustee & Guardian website www.tag.nsw.gov.au provides additional information.

As the treating practitioner, it is up to you to identify the person responsible and treat them accordingly. People do not have to be legally appointed to be the person responsible.

Sometimes, there may be a tribunal appointed guardian who has responsibility for consent and treatment decisions. You may need to check and see if a guardian is appointed and what their decision-making powers are.

As a person responsible or guardian, carers have the right to be provided with information on available services, treatment options and costs in a clear and open way by health staff.

In general, carers have the responsibility to be honest, open and ask more questions when they do not understand or require additional information. However carers who are also the person responsible or the guardian have the additional responsibility of ensuring they understand the nature and effect of any treatment requiring consent.

5. Health Issues for Carers

Carers tend to neglect their own health. Sometimes this is due to practical reasons; maybe they can't leave the home to attend GP and specialist appointments or hospital treatments.

Sometimes it's because they focus so much on the care of the patient that they simply pay no attention to their own health needs.

Whenever you see a carer with a patient, it is always worth asking the carer how he or she is. This may alert you to carer health problems, which you may be able to act on if the carer is your patient.

However, even if the carer is not your patient, a simple question such as this will make them feel they have been noticed and that you care about their welfare too.

Anecdotal evidence and carer research consistently demonstrates that caring has a pronounced adverse effect on psychological health.

- Carers have higher levels of distress and depression.
- Carers providing significant care per week over extended periods have a higher risk of psychological distress than non-carers; the risk of distress increases progressively with the amount of time devoted to caring evident beyond the end of caring episodes.
- The effects of caring on physical health are less clear, however we are aware many carers report back injury as a result of caring (for example, carers 'heavy caring' for those with physical disabilities who have compromised their backs and knees).
- Many carers put their high blood pressure down to the stress of caring.
- Older carers who report 'strain' have a higher likelihood of death in a four-year period than non-carers or carers not reporting strain.
- Providing high levels of care is associated with a higher risk of stroke.

Other risks specific to this population include a higher than average prevalence of self-harm for younger carers and abuse from the person cared for, particularly if the person has behavioural problems as a result of their condition.

Specific Issues for Young Carers

Much less is known about the health effects of caring on young carers than on adults. However, they may report:

- Feeling worried, anxious or stressed about caring responsibilities and the person they care for.
- Physical injuries (e.g. back strain or muscular injuries) as a result of caring duties.
- Missing healthcare appointments with doctors or dentists.
- Poor diet because of financial constraints on the family food budget, or because they have responsibility for preparing meals but lack basic cooking skills.
- Behaviour problems, particularly self-harm.
- Difficulties playing or socialising with other children, and joining in with sporting and leisure activities as a result of lack of time due to caring responsibilities and/or lack of parental support.
- High levels of bullying.
- Having ongoing difficulties establishing relationships.

For just over one in five young carers (22%), caring has a negative impact on education. Educational difficulties are more common in the 11-15 year old age group and include:

- Increased absences and/or lateness.
- Failure to submit homework or coursework, or poor quality work.
- Tiredness, poor concentration and/or lack of attention.
- Under-attainment which may restrict higher education options and long-term job prospects.

You should consider the need to involve the child's school. Find out if the school is involved or aware of the caring role the child has taken on.

Do they, or could they offer sensitive support? Discuss this with the young carer and family.

If the young carer and family are in agreement, contact the school nurse for help, or find out if the school has a teacher who supports young carers and contact that teacher.

If you are unable to spend time on this aspect contact the Young Carer Support Officer at Northern Sydney Local Health District on 9462 9488 who will assist the family.

When prescribing medication for any patient, always consider whether a young carer may be administering it. Is that appropriate? Does the young carer or family need support? Try to find ways of relieving the young carer of this responsibility or consider providing training for the young carer if appropriate.

“A major worrying task is that most young carers are responsible for giving out medication to the person they care for... they are worried one mistake could be fatal.”

6. Promoting Carer Wellness and Providing Support

There is a great deal GPs and primary health care teams can do to support and promote the wellness of carers. General strategies include:

- Providing adequate safety-netting and follow-up arrangements for carers and family members to reduce risk and improve care.
- Providing education for the patient, their carers and other family members about medicine management for the person they are caring for.
- Knowing the health effects of caregiving (including increased risk of cardiovascular disease and psychological distress), the social effects of caregiving (social isolation).
- Encouraging and enabling carers to have an annual influenza vaccination as a priority group.
- Promote carer education sessions and support groups as a way for carers to receive additional support.
- Encourage carers to take a break and seek counseling if the caring role appears to be impacting on their mental health and wellbeing.

Note: the Carer Support Service provides support to Carers and can be contacted on: 9462 9488

Specific strategies can include:

- Depression screening

Remember, a significant number of carers experience considerable psychological distress. Consider screening and referral to either a clinical psychologist or counsellor.

- Supporting Young Carers

Age-appropriate information can be helpful for young carers. Some issues they may have include:

- Can I catch it? Will it happen to me or not?
- What caused it? Why us? Is it my fault?
- Can I do anything to make it better?
- Will the person that I look after get worse or die?
- What should I do in an emergency?

7. Crisis and Trouble Shooting

Providing adequate safety-net and follow-up arrangements for carers and family members can help to significantly reduce risk and improve care.

Knowing and addressing the problems most commonly associated with breakdown in the caregiving relationship (i.e. behavioural problems, communication problems and incontinence) will help you to identify risk early and intervene directly or through referrals.

Tips for responding to emerging crisis situations

- Refer people promptly and effectively to appropriate services when required. (Details on the Carer Support NSLHD website www.nscarersupport.com.au)
- Treat situations where care in the home has broken down as significant events (e.g. because the carer or family is unable to cope) and explore ways in which the carer or family can be supported to continue caring. Contact Northern Sydney Carer Support Service on 9462 9488 for assistance.
- Consider referring the carer to the NSLHD Carer Support Service to access additional support and information to assist them in their caring role.
- Provide the A1 **Carer Information Panel** in your practice to raise carer awareness and help carers access information help lines. Contact Northern Sydney Carer Support Service for resources.
- Provide the **NSLHD Carer Support brochure** in your practice. This links carers to local support and information to help them in their caring role. Contact us on 9462 9488 if you need more.

8. Creating a Carer Friendly Practice

There are a range of basic approaches and practices that GPs and primary care teams can take can make a significant difference in the lives of carers and those they care for.

Tips for a Carer Friendly Practice

- ✓ **Create physically accessible premises.** Modify your building so carers can bring patients with a mobility condition or disability into your practice.
- ✓ **Listen to carer concerns** about the people they care for.
- ✓ **Ensure carers have access to after-hours medical support information** and that for complex patients, you have provided the carer with contact details for a GP cover whilst you are on leave. Note 13SICK for a GP to come to the home after hours.

- ✓ **Identify and support the role of person responsible or guardian** in situations where the patient is unable to provide his or her own consent.
- ✓ **Develop skills** for counselling, coaching, teaching and planning care with patients and carers, recognise continuity of care and effective long-term relationships are essential components of high quality care.
- ✓ **Offer carers consultations** at times when their caring duties permit them to access the GP surgery (or home visits if they are unable to attend the GP surgery because of caring duties).
- ✓ **Examine barriers to carer support** and ways in which they could be overcome within your field of practice; such as flagging the option for carers to participate in consultations.
- ✓ **Use the information systems** within your organisation to promote the identification of carers.
- ✓ **Put together and provide an information pack** for carers and family members to help them in their roles. Information can be provided by the NSLHD Carer Support Service.
- ✓ **Regularly obtain feedback** from carers on your appointment booking, referral and communication systems and use this information to improve access and continuity of care.
- ✓ **Value the views of carers** and acknowledge the barriers they face to providing effective support for the person they care for. Appreciate that factors affecting a carer's health may affect his or her ability to care.
- ✓ **Understand** that having an identified health professional to liaise with or the same GP to provide care can be immensely helpful for carers. It reduces repetition, saves time and is reassuring for the carer knowing the healthcare professional is familiar with, and understands the situation they're dealing with (even when the patient is not present).
- ✓ **Identify patients undertaking caring duties** and note the impact these duties have on their life, (eg at school, at work, at home or in the community). Support them to maintain their level of functioning, for example, liaising with the carer's employer if time- out is needed for caring duties.
- ✓ Be alert to the presence of carers under the age of 25 and provide support when a young carer is identified. Consider if they are undertaking caring duties inappropriate to their age. (This may be a safeguarding issue).

9. Life after caring

“For so long, it’s like I’ve been living in a dark tunnel that gets narrower, but now I’ve reached the light at the end, I feel completely blinded by it.”

The National Strategy for Carers encourages carers to maintain a life of their own but in reality their identity is likely to have been shaped by their role as a carer.

As a result, when their caring responsibilities come to an end, they question what else they are able to do. Time lost from education, employment, personal and family relationships will inevitably have affected the life choices of former carers. Ongoing support is needed throughout this period of time.

Problems commonly seen when carers stop caring include:

- Feelings of emptiness and void.
- Low self-esteem, depression, anxiety, and/or self-destructive behaviour such as alcohol abuse.
- Without the company of the cared for person, loneliness and more social isolation than before.
- Poor health as a result of years of self-neglect, back strain, lack of sleep and stress.

Every caring experience is different. How a person copes with life after caring depends very much on the length and complexity of the caring responsibility and the relationship between the carer and the cared for person. It also depends on how it ends:

Death of the care recipient may result in a sense of shock, even if the person has been ill for a long time. Benefits often come to an end within a few weeks of death and there may be housing issues if the person who has died owned or was leaseholder for a joint home.

Admission into residential care also results in a sense of bereavement. Often, such a move is the only feasible option but the carer may still suffer from feelings of guilt and anxiety. Even though the carer will continue to be a carer, albeit from a distance, he or she may feel a sense of failure. In addition, there may be financial implications and, after many years of rarely being able to leave home, the carer will lack confidence in seeking a life away from their caring responsibilities.

Varying care needs may result in carers moving in and out of a caring role. For example, where a family member misuses alcohol or drugs, has a mental health issue or an eating disorder, carer responsibilities will vary according to the current state of health of the person they care for. Even when that person appears to be coping well, the carer will always have the stress of wondering what the future will bring and uncertainty of not knowing when their help will be needed urgently.

10. Key contact details

Centrelink Financial Entitlements

Carers may be eligible for Carer Payment and/or Carer Allowance, therefore they should:

- Contact Centrelink on **13 2717**, or

- Visit their local Centrelink office, or
- Visit www.centrelink.gov.au to receive information on claiming the allowance.

To speak to Centrelink in languages other than English, carers should either call **13 1202** or visit a Centrelink Customer Service Centre and ask for an interpreter, or visit **www.centrelink.gov.au** and select 'We speak your language'.

Carer Support Service NSLHD - (02) 9462 9488

The Carer Support Service for the Northern Sydney Local Health District provides information, education and advice to assist carers in their caring role.

They can help carers navigate the health, community health and community care systems to find the right services in the Northern Sydney region.

Carers should contact the Northern Sydney Carer Support Service on tel. **(02) 9462 9488** 8:30am to 5:00pm Monday to Friday; or visit the website at: **www.nscarersupport.com.au**

My Aged Care 1800 200 422 www.myagedcare.gov.au

For all people aged over 65 years. My Aged Care provides access to community services and residential respite or full-time care. They also manage access to the Aged Care Assessment teams for assessment of Commonwealth subsidised care.

Disability Care - National Disability Insurance Scheme 1800 800 110

For people with a disability under 65 years of age. the National Disability Insurance Scheme (NDIS) commences in our region. Contact the above number to register for assistance.

For further information please see the National Disability Insurance Scheme (NDIS) website at www.ndis.gov.au.

Many people are opting to purchase care privately due to limited Government subsidised services, particularly for aged care at home. The Carer Support service will assist carers to navigate these two main aspects of care in our region. Contact us on (02) 9462 9488.

References

1. (Source: The Children's Society Include Project. *Supporting young carers and their families: Information for healthcare professionals* (2012).
2. GP Guide Supporting Carers – information has been used in this guide with kind permission of the Princes Trust UK.
3. Carer Recognition Act NSW 2010

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Contact us at Royal North Shore Hospital on 9462 9488 or visit us at www.nscarersupport.com.au



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Carers are the family member, partner or friend who provide care and support for people with a disability, a medical condition (including terminal or chronic illness) a mental illness or a frail aged person.

The Northern Sydney Carer Support Service provides information, education and guidance to carers either in the community or when a family member is in hospital.

Carer Support groups and carer education sessions in the Northern Sydney region are listed on the Carer Support Service website

www.nscarersupport.com.au

You can also call our service on **9462 9488** during office hours for further information.