Caring for carers

How GPs can help lighten the load

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Many of the 2.7 million unpaid carers in Australia neglect their own mental and physical health to focus their energies on the person they care for. This article explores carers' health issues and how they may present in general practice, including practical tips on how GPs can identify the stressors in carers' lives and find ways to reduce that stress.

Anybody can become a carer at any time. The role tends to land on people unexpectedly – a child has a disability, a family member has an accident or develops a disabling physical or mental illness, a parent or partner becomes dependent through frailty or dementia. People can find themselves working as unpaid carers, often for decades, due to devotion, expectations or lack of viable alternatives.

There are around 2.7 million unpaid carers in Australia. Most carers (about 70%) are female and of workforce age. Around one in 10 carers is aged under 25 years while many are past retirement age or even elderly. Over half of primary carers are not in paid jobs (Box 1).[1]

Many informal carers receive no assistance from formal support services and few belong to a carer support organisation. Some people find themselves caring for more than one person, simultaneously, serially or both, over the course of a lifetime.

KEY POINTS

- The carer may not present as having a problem.
- Stress is ubiquitous in caring; supportive listening is vital.
- Mental health problems are common.
- Physical health issues are those of the general population, as well as those caused and exacerbated by the caring role.
- The carer may put their health issues on the back burner.
- Support is available, but accessing it can be daunting.

Although many carers are initially bewildered, dismayed and oppressed by their caring duties, often taken on at a time of great personal distress, they soon become 'the expert' in the needs and rights of the person they are caring for. They have a right to be listened to and respected in discussions about care issues and management. This dedication to their duty of care can be a factor in the neglect of their own health and personal needs.

GPs are not always aware that a patient presenting with assorted stress-related issues has a caring role. Also, a devoted and busy carer may only ever present with the person they care for and that person's health or management problems. It is important to gently explore for stressors in people's lives and how they might be affecting their own health and wellbeing (Table).

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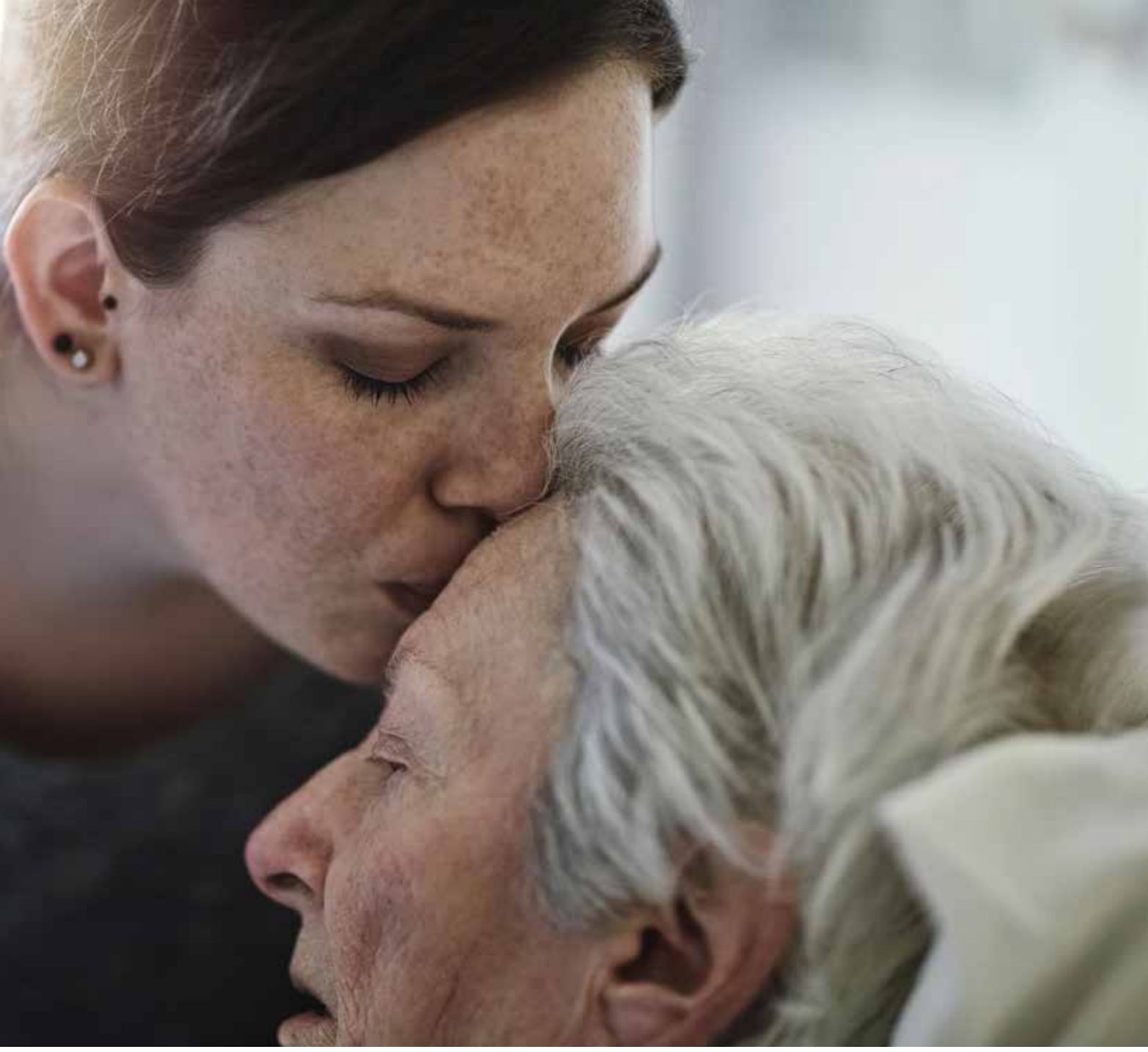

Mental health issues

Carers have significantly worse mental health and vitality and higher rates of depression than people who are not carers.[2]

Many carers lead highly stressful lives. On top of their existing responsibilities to family, work and community, they have taken on – or have had thrust upon them – the task of providing daily care for a family member or close friend.

Given their heavy workload, carers often find it difficult to allocate the time and energy to look after their own mental wellbeing so it is not surprising that they are prone to mental health problems. Stress can also exacerbate their physical symptoms.

1. CARERS IN AUSTRALIA[1]

In Australia in 2015:

- Almost 2.7 million or 11.6% of people were unpaid carers, with 856,100 people aged 15 years and over identified as primary carers
- The average age of a primary carer was 55 years
- Over one-third of primary carers (37.8%) were living with disability themselves
- Females made up the majority of carers, representing 68.1% of primary carers and 55.5% of all carers
- 56.3% of primary carers aged 15 to 64 years participated in the labour force compared with 80.3% participation for noncarers)

TABLE. ADDRESSING CARER ISSUES

Carer issue	Suggestions for GPs
Anxiety about giving medications, anxiety about medications not being taken properly by a person living independently	• Provide a drug sheet with dose, purpose and possible side effects included • Suggest using a dosette box or arrange Webster packing • Involve a visiting nursing service in giving medication • Discuss reminding and checking strategies
Anxiety about falls, safety at home, frustration that aids are not being used	• Refer to a falls clinic • Organise occupational therapist review of home situation • Organise physiotherapist review of mobility and aids • Authoritatively and repeatedly encourage the use of aids
Back pain, strain from lifting, tiredness	• Assess symptoms and treat • Organise physiotherapist review of techniques, advice and therapy • Organise occupational therapist review of required aids • Arrange support to obtain suitable aids and equipment
Exhaustion, not coping	• Be prepared to listen • Assess general health and treat as indicated • Review adequacy of diet, exercise and sleep • Assess for depression and manage if present • Provide information about support groups • Discuss strategies for getting more rest and respite • Explore eligibility for National Disability Insurance Scheme or Aged Care funding packages
Anger, frustration, resentment	• Be prepared to listen • Review adequacy of diet, exercise and sleep • Assess for depression and treat if required • Consider the use of unhealthy props – alcohol, junk food, drugs • Explore the possibility of abuse (by, or towards, carer) • Review supports in place • Provide information about support groups • Offer to talk to other family members, mediate at a family meeting or participate in a case conference • Consider a mental health review or behavioural assessment of the care recipient • Discuss options for alternative care
Anxiety about providing nursing care – dressings, incontinence care, bowel management, skin care etc	• Involve local home-nursing services • Refer to a continence clinic • Discuss training options (available through carer organisations in each state) • Seek appropriate funding package to cover care needs

Anxiety

Carers experience anxiety for many reasons. Most carers lack experience or training for their caring tasks. The person they care for may be deteriorating, terminally ill or at risk of falls, wandering or seizures. There are many competing pressures for the carer's time and attention (Box 2), and it can be difficult to set priorities and meet demands.

Although some degree of anxiety is understandable, it is important to explore the reasons for the anxiety and suggest ways of minimising the causes before the carer's level of anxiety interferes with their ability to function. For example, an occupational therapist's review of the household can result in modifications and aids to improve safety and alleviate carer anxiety about falls and wandering.

If anxiety persists, counselling or relaxation programs may be useful, or medication may be required. Discussing alternative care options may also be helpful. Evidence-based online treatments for anxiety, depression and stress can also be helpful for time-poor carers. These online services are immediately available, often free and accessible at home at a time that suits the individual (Box 3).

Depression

Depression is the most commonly identified mental health condition affecting carers. It is serious and can be life-threatening to the carer and/or the person they care for. Depression can present in many guises. GPs should consider depression whenever a carer presents with new symptoms or issues, such as sleep disturbance, loss of appetite, irritability, feeling overwhelmed or inadequate, or complaints that the care recipient is becoming too much for them to handle.

Like many people, carers can be reluctant to accept a diagnosis of depression because they may think it implies they are not coping. A careful explanation of the nature of depression and the effectiveness and importance of treatment is often necessary. It is important to review the burden

2. THE ROLE OF CARERS

Carers perform a variety of services including:

- Personal care
- Shopping, providing meals and feeding
- Housework, home maintenance and modification
- Managing and supervising medication
- Dressings and pressure care
- Incontinence management
- Home programs for physiotherapy and occupational therapy
- Organising and accompanying to appointments
- Providing and arranging transport
- Financial management
- Sourcing and arranging day programs, activities and respite
- Managing and maintaining complex equipment such as respirators, hoists, wheelchairs, drips and colostomies
- Formal decision-making as an appointed Guardian or Administrator
- Paperwork and case management for the National Disability Insurance Scheme or Aged Care Funding Packages
- Emotional support and nurturing
- Care during the night
- Maintaining records

of care and ensure that all available and acceptable supports are being accessed. Close follow up and monitoring is also necessary.

Grief

Grief for the loss of a loved one can occur without a death. When an infant is diagnosed with a serious disability, parents often experience prolonged and recurring grief at the loss of the perfect child they had anticipated. Similarly, when a person loses a parent or partner through cognitive decline, stroke or head injury, which changes them into an unrecognisable shell of the person they loved, grief can be as real as if the person had died. Empathetic listening, supportive counselling and, if necessary, referral or medication are appropriate. Grief may recur, such as at anniversaries of former family celebrations, and the GP needs to be ready to listen and provide support repeatedly over the years. When a dependant finally dies, the carer's grief can be complicated by a complex mix of guilt-ridden relief and the loss of role and occupation. The carer may need professional counselling to help them move on.

Stress

Many patients seem more comfortable with the concept of experiencing stress than with diagnoses such as anxiety or depression. Many aspects of the caring role can precipitate feelings of stress

3. EVIDENCE-BASED ONLINE TREATMENT SITES FOR ANXIETY, STRESS AND DEPRESSION

- **myCompass, Black Dog Institute**
  www.mycompass.org.au
- **Mindspot, based at Macquarie University, Sydney, and funded by the Federal Government**
  www.mindspot.org.au
- **eCentreClinic, Macquarie University, Sydney**
  www.ecentreclinic.org
- **This Way Up, St Vincent's Hospital, Sydney**
  https://thiswayup.org.au

CASE SCENARIO 1. CARER STRESS AND SOMATISATION

Lorna, aged 65 years, cares for her husband, Fred, who has residual problems with the use of his right arm and emotional lability after a stroke. Whenever she sees her GP, Lorna has multiple complaints, including phlegm, itchy spots, indigestion, aches and pains and thinning hair – to name a few. Her consultations leave the GP wondering whether her symptoms fit with her known conditions (pernicious anaemia, mitral valve disease, hypertension and osteoporosis) or whether something new is developing and she should investigate further.

Lorna asks the GP: 'Could it be stress, doctor? It's Fred, you see …', and she tells the GP how difficult it is to care for Fred because he can be nasty, irritable and impatient with her. The GP listens to Lorna and empathises with her, classifying the itchy spots and phlegm as stress. However, among Lorna's many symptoms, there could be one symptom that indicates something needs to be diagnosed and dealt with.

The GP is aware he needs to be alert to real clues and keep a record of all of Lorna's symptoms so that any emerging trend is apparent. He suggests an Aged Care Assessment to review the level of support that the couple needs, gives Lorna information about Carers Australia, and monitors her health and wellbeing with regular reviews and judicious use of investigations.

(Case scenario 1). The cause of stress should be identified and dealt with where possible. Stressors include personality change in the person being cared for, especially when manifesting as verbal or physical aggression, repetitiveness, incontinence or disturbed sleep. Carers can also be stressed by boredom, frustration, tiredness and financial strain. Possible solutions depend on the cause but often just listening is helpful.

Guilt

Guilt is often part of the carer's load. Parents can feel that they were in some way to blame for their child's problems, and partners and adult children may dwell on negative incidents with the person they care for and regret past behaviour towards them.

When the caring role has been taken on with a degree of resentment or reluctance, the carer can feel a continuing complex mix of guilt, anger, hurt and resentment that can undermine their emotional welfare and impair their capacity to make rational judgements about their caring responsibilities and their own wellbeing. For example, they may refuse to consider respite care when they need a break, or they may defer investigations or surgery recommended for them. When a doctor gets the impression that guilt is affecting a carer's functioning, it can be useful to help the person confront and openly evaluate their mixed feelings.

Emotional and physical abuse

The relationship between the carer and the recipient of care can be fraught. It can be complicated by factors such as exhaustion, hostility, negative past relationships, pain, sleep deprivation and depression in the carer; and agitation, repetitiveness, memory loss, frontal lobe deficits, pain, disturbed sleep, emotional lability, ingratitude and mental illness in the person being cared for.

The potential for abuse by either or both parties depends on the power balance and the resilience of their personalities. Both parties may seek to hide an abusive relationship. If a health professional suspects high levels of stress may be resulting in abuse, gentle but direct probing to open up the topic may lead to discussion and some resolution. It is helpful to comment that it is not surprising how the situation could well lead to impatience and anger. If this is acknowledged, follow up with questions about what actually happens when anger builds up. If the person feels their confidence will be accepted and respected, they are more likely to admit they sometimes lose control.

If the GP suspects abuse is occurring with the potential of risk to either party, it is important to take active steps to prevent harm and rectify the situation. Most states and territories have legislation relating to confidential mandatory reporting of neglect or abuse of children, people with disabilities and the elderly, and there are 24-hour hotlines to contact for advice. It may be necessary to arrange emergency out-of-home care if the risk of harm is perceived as high. Certification and police involvement may become necessary. If the carer is the party at risk of harm, the GP needs to assess their ability and willingness to take steps needed to protect themselves. If they are too oppressed to do this, the involvement of outside agencies may need to be arranged.

Drug and alcohol abuse

Another potentially harmful result of stress for the carer is the temptation to resort to alcohol or medications to get through the day. The stress of being a carer may exacerbate a pre-existing tendency or set off a new problem. Drug and alcohol abuse can impact on the health and wellbeing of both parties in the caring relationship. GPs need to keep this possibility in mind and seek to intervene before the habit becomes an addiction. Questions about coping strategies can be followed up with more direct questions about any tendency to use alcohol, including how much and how often.

Any prescriptions of benzodiazepines need to be monitored carefully to prevent a gradual increase in use. Short-acting benzodiazepines, such as temazepam, may be helpful for initial insomnia but only for short periods, after which tolerance typically develops. Prescription of benzodiazepines for anxiety is best avoided.

Other mental health issues

Carers may have pre-existing mental illnesses or develop these in the course of their caring life, so it is important not to attribute all behaviour change and expressions of distress solely to the high level of

stress affecting the carer. For example, GPs will be aware that mood and anxiety disorders are common in the general population and psychotic disorders can also develop for the first time in middle and older age.

Physical health issues

It is important for GPs to be alert to carers' physical health issues as they may be reluctant to raise them, focusing instead on the needs of the person they care for. The self-rated physical health of carers is significantly poorer than that of the general population.[2]

Musculoskeletal problems

Informal carers are usually not trained in lifting methods and do not have the same protections that occupational health and safety regulations provide for paid carers. An unpaid carer's role can involve awkward and heavy lifting, injury from catching a falling person, and restraining someone who is aggressive or resistant. Parents of a child with a disability can find themselves still lifting and carrying that person when they are an adult. Older carers may already have poor muscle strength, osteoporosis and arthritis when they take on the role. Musculoskeletal trauma and pain can be the straw that breaks the back of a long-time caring relationship, and may mean the person has to be transferred to out-of-home care.

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Aids and supports to help with lifting, transferring, bathing and mobility are important resources. The GP needs to be proactive in suggesting and/or facilitating the timely provision of equipment to help prevent musculoskeletal injury. An occupational therapist, from an Aged Care Assessment Team, the National Disability Insurance Scheme or a community health centre – or a private therapist – can assess what is needed and advise on how to obtain it.

Nutrition and obesity

It is easy for a busy carer to develop a pattern of poor nutrition. Snacking, making do with a bit of meals they have prepared for the person cared for, or consoling themselves with cakes and lollies can lead to nutritional deficiencies and obesity. When the diet is haphazard and opportunistic, conditions such as anaemia and osteoporosis can develop. If the carer is largely housebound by their duties, vitamin D levels should be checked. It is important to be alert to weight changes and regularly reinforce the importance of a healthy, balanced diet for general wellbeing, ability to cope and disease prevention. When reviewing a carer's diet and weight, it is worth emphasising the benefit of regular exercise for both physical health and stress management.

Cardiovascular and respiratory conditions

Smoking may be an entrenched habit or a new diversion for carers. The carer should be supported to quit smoking and encouraged to find other ways of coping with stress, such as enjoyable exercise and activities, time out or counselling. Carers may feel they are too busy to have checkups or to see about symptoms such as shortness of breath, oedema, palpitations or headaches. The GP may need to be assertive and proactive in suggesting they make an appointment to have blood pressure and urine checked and a systems review.

CASE SCENARIO 2: ESCALATING STRESS

Meg and Alec, a professional couple, have been happily married for nearly 50 years. When Alec's degenerative condition became so severe that he needed a lot of physical assistance, Meg retired and became his carer. They managed well with home modifications and outside support until a new medication precipitated an episode of acute mania (Alec had previously undiagnosed bipolar diathesis).

The mania did not subside when the condition was diagnosed and the new medication was ceased, with treatment achieving only partial resolution of his bipolar symptoms. Meg is now not only doing full physical care but caring for a partner who is sleeping very little, talking constantly about his grand plans, and becoming annoyed and hostile. Her stress levels have increased despite greater support and respite arrangements and their relationship has become fraught. Meg becomes distressed when telling her GP that Alec is pressing her to sign cheques (as his Enduring Power of Attorney) for large amounts of money. She wants to refuse as he is not making financially sound decisions. The GP suggests Meg do a depression screen and offers to talk to Alec. He provides Meg with information about carer support groups and the Office of the Public Advocate, and offers a referral to a counsellor. He asks Meg to see him again in two weeks.

Gastrointestinal problems

Stress, poor diet, inadequate fluid intake, lack of regular exercise, excessive bending and lifting, medication, smoking and alcohol use can make carers vulnerable to a range of gastrointestinal disorders, including gastro-oesophageal reflux disease, ulcers, constipation and hernias. If they are not encouraged to have regular health checks, carers may neglect early symptoms of conditions such as gastrointestinal malignancies and inflammatory bowel disorders and present with advanced disease.

Dementia and other neurological conditions

The GP needs to keep in mind that behaviour change may be due to problems other than the stress of being a carer so that early changes of neurological conditions such as Alzheimer's disease are not missed, especially in older carers.

Preventive health care

It is recommended that elderly people and people with chronic health problems or disabilities have a thorough annual check-up.

Carers, even young healthy ones, should be actively encouraged to make an appointment for a long consultation for themselves.

An annual health review should cover:

- diet and exercise
- immunisations
- relevant screening tests – e.g. Pap smears, mammograms, vision, hearing and dental checks
- depression and anxiety screen
- sleep pattern, weight change
- alcohol, tobacco and drug use
- medication review
- systems review
- physical examination
- investigations and referrals as indicated by findings
- support services indicated.

Financial and legal issues

Carers may ask their GP for advice and support to deal with financial and legal issues for themselves or the person they care for. There may be disputes in the wider family about what is in the person's best interests and who should pay for support. This may call for great tact, especially if the carer, the person being cared for and the disgruntled family members are all the GP's patients. There can be issues relating to confidentiality and conflict of interest, and the GP should seek advice and independent input if commonsense is not enough to sort things out.

GPs may be called on for input into preparing Enduring Powers of Attorney, Medical Powers of Attorney and applications for formal Guardianship or Administration appointments (Case scenario 2). Financial and funding support for people with disabilities and for carers is complex, and obtaining it can be very stressful and time consuming. GPs can be involved in providing reports about level of disability and anticipated care needs as part of the process. MT

References

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2. Australian Institute of Family Studies (AIFS). The nature and impact of caring for family members with a disability in Australia. Research report no. 16 – June 2008. Melbourne: AIFS; 2008. Available online at: https://aifs.gov.au/publications/nature-and-impact-caring-family-members-di/executive-summary (accessed March 2018).

Further reading

Dr Mary Burbidge, *Forever baby: Jenny's story: a mother's diary*, Harper Collins. E-book available from: www.harpercollins.com/9780007549115/forever-baby-jennys-story-a-mothers-diary

COMPETING INTERESTS: None