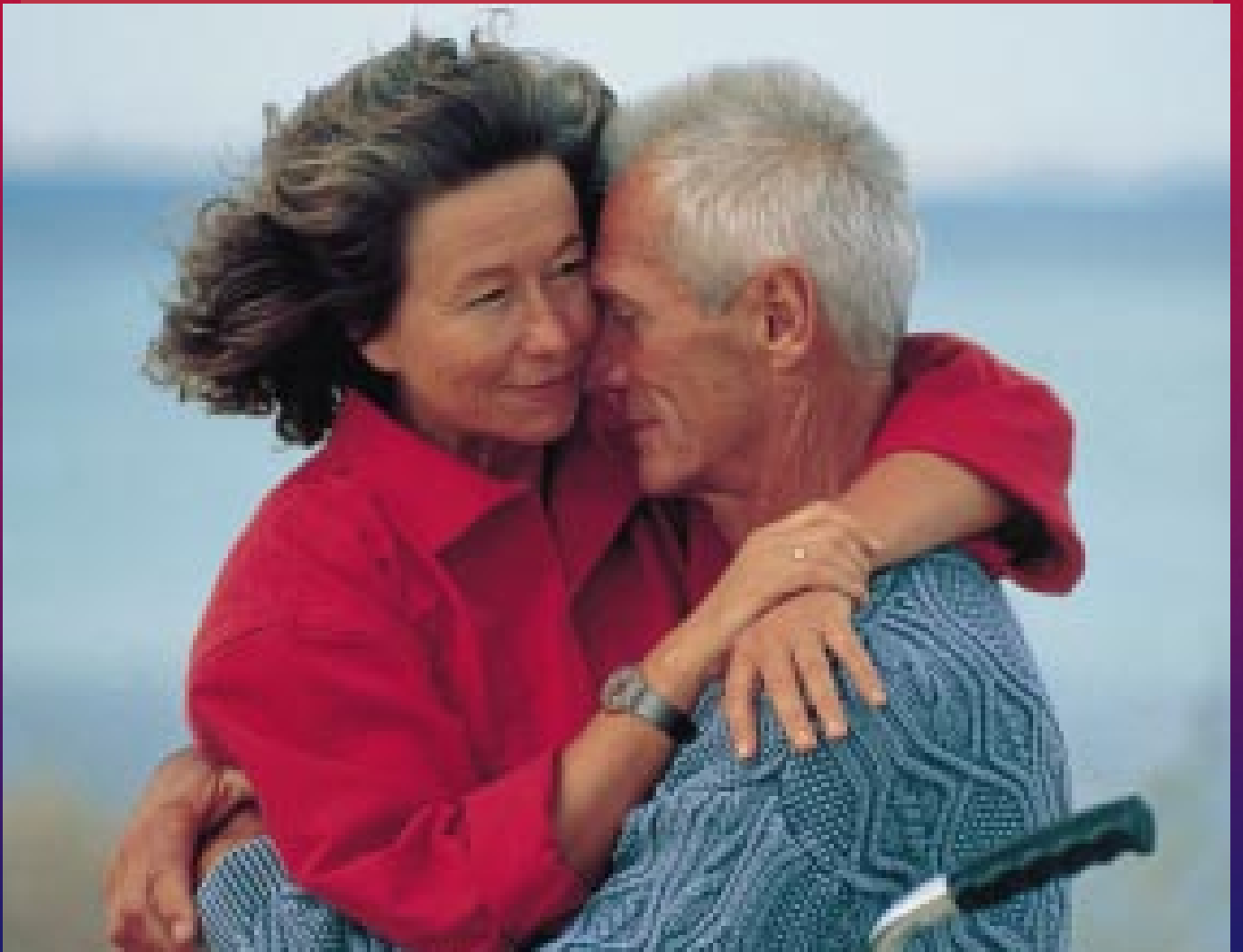


# *How Should We Care for the Carers?*



*Better support for those who care  
for people with disabilities*

**NATIONAL  
HEALTH  
COMMITTEE**

NATIONAL ADVISORY COMMITTEE  
ON HEALTH AND DISABILITY  
HUNGA KAITIHIRO I TE HAUORA O TE TANGATA

**National Health Committee**  
June 1998

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## SUMMARY

This booklet looks at what can make life easier or more difficult for those who care for people with disabilities.<sup>1</sup> We hope reading it will **help you** understand and debate the issues, and **help us** recommend ways of making things better for those who care for others with disabilities. While the focus is primarily on people with disabilities, we acknowledge the role of those who care for people with what are generally defined as 'personal health' problems.

Increasing numbers of people with disabilities in this country are being **cared for at home**. This is mainly because people with disabilities have 1) increasingly become part of the community, 2) been moved out of institutions, and 3) been kept out of long-term hospital or reshome care. New Zealand carers' work goes mostly **unrecognised and unpaid**. It's most often the responsibility of family members and others who live with or near the person being cared for.

### This booklet is in two parts:

- **section one** suggests strategies to bear in mind while reading section two - they should start you thinking; come back to these when you've read section two.
- **section two** is based on what's been written about carers and what they've said during national consultation; it describes what caring for people with disabilities is like, and what the benefits and costs of carers' work are; it suggests the support carers need in terms of practical help, recognition, time away from caring, and financial support and planning.

We suggest several ways of supporting carers better, and look for **your comments on**:

- making information more available
- improving hospital discharge planning
- improving needs assessment,



including ways of developing integrated care packages

- improving development of services such as respite care, and making services and access to them better and fairer
- improving relationships between carers and health professionals
- carer training.

Clearly health and disability resources are limited and large injections of extra funding are unlikely. Most of these ways of helping don't cost money. Where they do, we recommend **weighing costs against benefits** so we can all know if a particular strategy is a good way of using extra resources.

Australia recognises the work carers do by paying them if they qualify by a means test. We ask if this is a good idea for New Zealand (*see pages 20-21 for more details*). We raise the possibility of a **carer support brokerage service** to budget hold and provide carers with better support (*see page 25*). Brokers would be responsible for assessing eligibility and providing access to integrated services. If such a move were adopted in New Zealand it would need to be aligned to improvements in existing service coordination structures.

<sup>1</sup> A disability limits or impairs a person's activities and ability to participate. An impairment is a loss or abnormality of psychological, physiological or anatomical structure or function. A disability is defined as lasting for more than six months, and may be physical, sensory, intellectual, psychiatric or caused by an age-related frailty. Statistics New Zealand's 1996 household disability survey found most people with a disability reported having more than one.

It's important to remember this booklet is intended to prompt discussion and that we're **looking for your response**. All responses will be analysed and form the basis of our recommendations. We hope those thinking about and commenting on the issues we raise will include:

- carers
- those they care for
- those currently providing support services
- those making policy and funding decisions.

## About this booklet

### This booklet:

- **describes** what carers do and what they need
- **suggests** what's hindering them from having their needs met
- **helps** the National Health Committee<sup>2</sup> find out what people think about how carers could be better supported
- **will be circulated** to carers, people with disabilities, funders, policy makers and providers of support services, whose responses will be analysed and become the basis of recommendations.

**The main part** of the booklet discusses:

- what we know about caring work in New Zealand
- what carers need and what can stop them getting what they need
- some strategies for meeting carers' needs.<sup>3</sup>

Information in this booklet has been taken mainly from:

- what's been **written** in this country and overseas about caring
- **consultation** undertaken by the National Health Committee.

**Consultation** took place during late 1997 with six groups of carers from different places and representing a range of caring experiences. They included those who care for:

- people with head injury
- children with disabilities
- older people with dementia
- people with disabilities in the country
- people with schizophrenia
- people with multiple sclerosis (MS).

**Discussion** was informal and open-ended but revolved around three questions:

What's your experience of providing care?

What's your experience of service provision and delivery?

What suggestions or ideas do you have for improving service delivery?

Stories and experiences shared in these meetings were useful insights into **what carers do**. Carers talked about interactions with funders and service providers, and had good ideas about which services could be tailored to meet their needs. Where we refer to these carers' stories in this booklet we preserve their anonymity and privacy.

The National Health Committee gratefully acknowledges the carers who made themselves available for consultation meetings and shared personal experiences. Marg Gilling, BERL, prepared background information used in this report.

*2 The National Health Committee's Terms of Reference require it to provide the Minister of Health with advice on the kinds and relative priorities of health and disability support services which should, in the Committee's opinion, be publicly funded. The Committee, as part of its work, consults with the public to ensure funding decisions on provision of services are fair and wise.*

<sup>3</sup> No cost benefit analysis has yet been undertaken for this report. Most suggested strategies involve 1) improvements to existing services, which can be funded from existing budgets, or 2) re-allocation of available funding. Funders (including ACC, the Health Funding Authority, New Zealand Income Support Service, Community Housing, the Community Funding Agency, voluntary agencies and some local authorities) are expected to undertake their own financial risk analysis for any new service.

## SECTION ONE – STRATEGIES FOR DISCUSSION

Please cut out and  
return this section

### Introduction

#### The purpose of the discussion

The National Health Committee is seeking feedback from a wide range of groups and individuals on the strategies proposed about how carers can be better supported. The feedback will then be used to inform the Committee's recommendations to the Minister of Health.

Basic information on the work of carers, the stresses they may experience, and various types of support services which can help to minimise these stresses follows. The material is drawn from a review of national and international literature and from consultation with a selection of informal carers in New Zealand. The report concludes with a summary of possible strategies for improved support to carers in New Zealand.

We ask respondents to rate the strategies according to:

- whether the strategy relates to a major need which is not currently met;
- the importance of the strategy for relieving carer stress and supporting carers;
- the feasibility of the proposed solution.

Respondents will also be asked to give brief reasons for their responses if they wish. This feedback will enable the Committee to consider which areas should receive priority attention, to suggest feasible solutions, and to investigate possible cost implications of any proposed changes.

#### Those involved in the discussion

The National Health Committee seeks feedback from a wide range of persons and organisations affected by the issues of providing informal (unpaid) care and support to people with disabilities. Feedback is therefore sought from:

- carers;
- people receiving care and support from informal carers;
- general practitioners;
- home support providers;
- carers' organisations;
- disability organisations;
- respite care providers;
- needs assessment and service coordination providers;
- policy advisers;
- funders/purchasers.



## THE STRATEGIES

The questions are phrased as statements. For each discussion statement that follows, please note its importance on a scale from 1 (low) to 5 (high) for each of the following:

- current unmet need
- value of strategy for relieving/minimising carer stress
- feasibility or practicality of the strategy

1	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	Providing information packs to carers in their early stage of caring is an important strategy to pursue			
Comments/justification				

2	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	Any discharge of a person with a disability or chronic illness from a health or disability service should include a comprehensive discharge plan developed in consultation with a primary carer			
Comments/justification				

3	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	The needs assessment service should focus on carers' needs and stresses as well as the needs of the person with the disability			
Comments/justification				



4	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	Publicly funded carer relief should be available for <b>all</b> carers throughout New Zealand on an equitable basis, and provide for flexible and individualised carer relief			
Comments/justification				

5	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	The coordination and prioritisation of various carer support services could be improved by the use of brokers to ensure the most appropriate 'mix' of services for the individual carers			
Comments/justification				

6	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	Improved training is needed for health professionals to ensure that carers are recognised and appropriately consulted and involved when caring for a person with a disability or chronic illness			
Comments/justification				



7	STRATEGY	UNMET NEED	VALUE	FEASIBILITY
	Training programmes should be widely available to carers, designed to cover issues common to all carers and specific issues for carers of people with certain types of illness or disability			
<p>Comments/justification</p>				

8 Is there any other issue on which you wish to comment, that is not included in these statements? Please provide your comments below. Further space available on page 28.

Please send responses to:  
 'Carers'  
 The National Health  
 Committee  
 PO Box 5013  
 Wellington  
 by 30 September 1998.



## SECTION TWO

### WHAT IS CARING?

There's no hard and fast **definition of caring** but in this booklet we mean caring for a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support. While we acknowledge its limitations, we have chosen to address carers generally rather than focus on the distinctive circumstances surrounding different age groups and categories of disability.

The sort of caring we discuss is not usually based on any formal agreement or service specifications. Caring can be the carer's **main occupation**. Carers may have given up full-time paid work to provide care, or they may be juggling caring with paid employment and family commitments. Caring can include supervision and support, help with shopping and housework, transport to appointments, and help with getting out of bed, dressing and washing. It may take only an hour or so of a carer's time each week, or be a 24-hour-a-day, seven-day-a-week job. Caring involves **being there** even if the physical work commitment appears to be small. Further, the sort of caring we discuss does not stop just because the person being cared for moves into residential care.

Caring, in many situations, begins where the practical (but not necessarily emotional) give and take - the **reciprocity** - of everyday life ends, and the carer is giving more than they can ever hope to receive in return from the person they care for.

A study carried out in Auckland shows that it **costs more** than was originally anticipated to care for people with disabilities at home (Belgrave and Brown, 1997). It looked at first as if caring for people at home would be up to 30 percent cheaper than keeping them in a resthome, hospital or institution. But it involves other kinds of costs which are difficult to calculate because:

- caring often goes on **behind closed doors** and is mostly unseen



- carers often don't count the **personal costs** of caring
- **funders** (including ACC, the Health Funding Authority, the New Zealand Income Support Service, Community Housing, the Community Funding Agency, voluntary agencies and some local authorities) haven't yet worked out how to use what funds they have<sup>4</sup> to give carers the best kind of support.

If carers didn't give their services for nothing, caring for people with disabilities would cost taxpayers a great deal more than it already does. So it's vital we look at **what services carers need** to allow them to keep on doing their unpaid work which may be a lifelong commitment.

The challenge for funders, policy makers and service providers is to know exactly what services to provide. We hope this booklet will be a step towards helping them help the carers.

<sup>4</sup> Available funding relevant to carers is for home support, attendant care, domestic (domiciliary) purposes, respite care, transport, equipment, accommodation and vocational services.

## WHAT WE KNOW ABOUT PEOPLE WITH DISABILITIES AND THEIR CARERS IN NEW ZEALAND

### Disability Counts

Although we don't have much information about carers and their work, *Disability Counts*, recently published by Statistics New Zealand, contains some **useful facts** contributing to the picture of carers and their work. The information in *Disability Counts* most relevant to carers is about people with disabilities who live in households, as opposed to residential facilities such as resthomes.

- **One in five New Zealanders living in households has a disability** - more than 674,000 children and adults living in households report at least one disability; this is about 19 percent of the total population living in households.
- **Family is an important source of support** - 44 percent of adults with disabilities in households get help with everyday activities. More than 36 percent need help with heavy housework (like lawn mowing), 23 percent need help with everyday housework (like cleaning and laundry), 18 percent need help with shopping and 13 percent need help to prepare meals. For those who get help, most (65 percent) comes from family members.
- **Disability increases with age** - 11 percent of children (0 - 14) have a disability, increasing to 25 percent of adults 45 - 64, and more than half those 65 years or older.
- **Difference in disability rates between the sexes is greatest for children** - more than 13 percent of boys under 15 report some level of disability, compared with only nine percent of girls the same age. This difference disappears with advancing age, with men between 15 and 64 in households showing a disability rate of 16 percent, and women, 17 percent.
- **Physical impairment is the most common adult disability** - 67 percent of adults with disabilities in households have some kind of physical disability; nearly 43 percent have a sensory disability, which includes seeing and/or hearing impairment; psychiatric or psychological disabilities affect 13 percent of adults with disabilities, and about three percent have intellectual disabilities. Just over a third of adults in households say they have a long-term condition or health problem making it either impossible or difficult to do everyday things people their age usually do.
- **Children with disabilities are likely to be restricted at school or play, or in other activities.** A third of all children with a disability have chronic health problems, like severe asthma, lung conditions or cancer.
- **Disability rates are highest in the south, lowest in the north** - people in the southern Health Funding Authority region report a disability rate of 24 percent, compared with 16 percent reported by the northern population.
- **Urban/rural differences are greatest among people aged 45 - 64** - the likelihood of having a disability doesn't vary much between town and country for those under 45. But people aged 45 - 64 in rural areas are more likely than their urban counterparts to be affected by disability - 30 percent compared to 24 percent. At 65 and over the reverse is true, with half of those living in urban areas reporting some form of disability, against 44 percent in rural areas (probably because older country people move to residential facilities in town).
- **People with disabilities are slightly less likely to be part of a couple** - 62 percent of adults with disabilities living in households have partners, including legally married, de facto and other relationships. Nearly 66 percent of adults without disabilities in households have partners.

- **Severity increases with age** - the chances of being severely limited by one or more disability increases with age. Only seven percent of adults with disabilities aged 15 - 44 are severely limited by a long-term condition or health problem, but almost 20 per cent of those 65 and older in households or residential facilities have disabilities like this.

- **People with disabilities are less likely to be employed** - 213,800 adults with disabilities are employed: that's 37 percent of adults with disabilities in households. Almost a quarter need special equipment or services to be able to do their job. By comparison, 66 percent of adults without disabilities are employed. Adults with disabilities are more likely not to be in the labour force. Just over a quarter of the total working age population (15 years and older) are not in the labour force, but more than 60 percent (348,400) of adults with disabilities don't work and aren't actively seeking work. More than half these people are under 65.

- **People with disabilities have lower personal incomes** - given this labour force situation, the total personal income of those with a disability is significantly lower than that of adults without a disability. Sixty percent of adults with a disability report a gross personal income of less than \$15,000 for the year ended 31 March 1996. Forty-five percent of those without a disability earned less than \$15,000. Fewer than 15 percent of adults with a disability earned \$30,000 or more, while 27 percent of those without a disability said they were in this income bracket. **Women** with a disability have the lowest incomes. Seventy-one percent report an annual income of less than \$15,000, compared with just under half of men with disabilities. Only eight percent of women with a disability earned more than \$30,000, compared with more than 22 percent of their male counterparts. This pattern is reflected in household income. Adults with disabilities are almost twice as likely



to have a household income less than \$30,000 as those without disabilities.

- **People with disabilities are likely to have unmet needs** - many people with a disability need assistance or a service they're not getting, such as medical treatment, help with personal care, housework, shopping and special equipment. Nearly a third of all children and adults with disabilities report an unmet need for at least one type of service and/or assistance as a result of their disability.
- **One in five people with disabilities get government financial support** - 20 percent of adults and children with a disability received some kind of disability benefit in the 12 months before the 1996 Household Disability Survey: either sickness or invalid's benefit, disability or handicapped child's allowance, war disablement pension or special needs grant. Seven percent of all adults with disabilities also received



regular ACC payments. Seventy-two percent of children with disabilities and 65 percent of adults with disabilities held a community services card in the year prior to the survey.

We can make assumptions about those who care for people with disabilities based on the information in *Disability Counts*, but it's risky to do so, and we recommend more surveys and analyses to find out:

- how many carers there are in New Zealand
- how their time is spent providing care<sup>5</sup>
- the effects of caring on carers' lives.

### How much caring and how many carers?

Several New Zealand studies have focused on people caring for the elderly, and two show the extent of caring.

Abbott and Koopman-Boyden (1994)

Three thousand older people were surveyed by telephone, revealing:

- four percent gave an average 40 hours a week regular unpaid in-home care<sup>6</sup> for **older people**; 1.6 percent gave at least four and up to eight hours care a week; 1.2 percent gave 8 - 42 hours; and 1.2 percent gave more than 42 hours care a week
- twenty-six percent of the adult population care for someone **outside their home**

<sup>5</sup> The Time Use Survey being conducted by the Ministry of Women's Affairs and Statistics New Zealand in 1998/9 is expected to include information about how many carers there are in this country and how much time they spend providing care.

<sup>6</sup> Regular unpaid in-home care is defined as at least four hours unpaid care per week, on a regular basis.

- carers had, on average, been **giving care for almost six years**
- forty-two percent provided care **on their own**
- nearly 60 percent said if they didn't provide care, a hospital or resthome would be the only option, suggesting they provided **a high level of care**
- care was given **by the old for the very old**: most carers were 65 - 74, next were those older than 75, then those aged 55 - 64
- most carers were **either retired** (nearly all over 55) **or unemployed** (mainly young adults)
- most carers are the **spouse or off-spring** of the person they care for.

### Belgrave and Brown (1997)

This study compared the cost of care in the home with resthome care for elderly people. One hundred and eighty-six people took part: 95 lived in resthomes, 91 in the community. The study found:

- few carers (6 percent) were **under 40** years old; slightly fewer than 60 percent were between 40 and 60; 12 percent of in-home carers and 8 percent of resthome carers were older than 80
- most carers (just under 80 percent) were **women**
- nearly all carers were **related** to the person they cared for: 60 percent were their off-spring, and 23 percent their spouse
- about a third of carers were **retired**; of the others, 44 percent were in full-time and 32 percent in part-time paid work; 24 percent were unemployed.

These two studies and other research (eg. Sainsbury, 1997) have found carers' responsibilities don't end when the person they care for begins living in a resthome.

It's difficult to say **how many carers** there are in New Zealand, but their numbers will need to increase as the

number of people needing care in the community rises due to:

- people, including those with serious disabilities, tending to **live longer**
- the increasing proportion of **elderly** in the population (structural aging)
- people choosing to live in their homes longer (supported by **'aging in place'** policy and practice)
- the shift away from institutional towards **community-based care**
- people being **discharged from hospital** earlier (Abbott & Koopman-Boyden, 1994).

However as the number of people needing care grows, the pool of **available carers** shrinks. Research here and overseas suggests this is because:

- caring is no longer seen as a 'natural' extension of **women's role** and responsibility
- many women are in the **paid workforce** and can't or won't accept the burden of caring
- **parents** are often faced with caring for aging parents and children simultaneously, and this is more of an issue when childbearing has been delayed
- many families are **geographically separated**
- divorce and separation have broken **traditional networks** of care (Abbott & Koopman-Boyden, 1994).

## What do carers do?

The **relationship** between the person giving care and the person receiving it is often based on love, kinship or friendship, and usually exists before the need for care. So it's sometimes difficult to distinguish between 'caring' and ordinary parenting or support for family or friends. It's even harder to distinguish when the level of support increases gradually over time, which often happens without carers being aware of increasing demands.

The support carers give includes:

- **personal** - dressing, bathing, toileting

- **physical** - helping with walking, getting in and out of bed, lifting
- **safety and protection** - supervision of someone who might wander, providing a safe home environment
- **household** - preparing meals, shopping, housework, repairs, gardening
- **administrative** - paying bills, arranging appointments, finding appropriate services and entitlements
- **transport** - to appointments, services, shopping, social functions
- **social** - companionship, outings, additional teaching of basic life skills to children with disabilities
- **emotional** - support, encouragement, reassurance, counselling
- **spiritual** - praying, listening to concerns about dying.

Some caring activities are routine and regular, while others are less predictable eg. responding to a medical emergency or coping with grief (Belgrave & Brown, 1997).

The **experience of caring** can't be conveyed by a simple list of caring activities. Providing some kinds of care may be embarrassing, difficult, stressful, expensive, boring and exhausting for the carer. On the other hand, the provision of care can be emotionally rewarding for the carer. For many carers the emotional bond between them and the person they



care for is the most fulfilling and significant aspect of their lives.

The person receiving care may not always acknowledge what's done for them or appreciate the carer's efforts. But even if the person cared for is very appreciative, it may not significantly relieve the **stressful and often monotonous** experience of providing care.

Research has tended to focus on observable elements of caring and support services which reflect them eg. personal care provision and help with bathing and showering. But three New Zealand studies have identified **emotional support** as one of the most common caring activities (Tennstedt & McKinlay, 1989 in Lungley, 1995; Belgrave & Brown, 1997; Abbott & Koopman-Boyden, 1994). Carers often have to juggle different kinds of caring while trying simultaneously to maintain their existing relationship with the person receiving it.

*'He has seizures, he often feels trapped, so I have to be more of a nurse, a counsellor. I have to be a mother when he is unable to do even simple things without getting them wrong, to remind him of events and facts, people he has met or things he said he wanted to do. In fact, I need to think for him and sometimes feel as if I am two people.'*

*- carer's story*

## What sorts of care do carers provide?

How much care is given depends on how much the person being cared for needs, how well the carer can give it, and how extensive support networks are eg. friends, family, voluntary groups and formal service providers. Typically **support networks** were small and non-existent for those we consulted.

**Levels of care** can be measured in the number of hours committed or in the intensity of support provided. In most cases, one person - the primary carer - provides most of the informal care, which involves:

- a range of activities from intensive

round-the-clock care through to continuing paid work and living in separate accommodation

- active **tasks** for hours each day or week
- a continuing sense of **responsibility**
- a big **time commitment** - carers often underestimate how long they spend on caring and how much work they do
- **commitment** beyond normal levels of reciprocity.

*'Many carers had not thought of the care they gave as a distinct activity, but [saw it as] "part of the daily round".'*

*(Belgrave & Brown, 1997)*

The **primary carer** is vital to the survival and wellbeing of the person receiving care (either by directly providing it or by coordinating support networks). Informal helpers give practical assistance to friends, neighbours and less close relatives for relatively few hours but often over long periods of time (Parker & Lawton, 1994).

## What does it mean to be a carer?

Caring has costs and benefits.

**Benefits** include the enrichment of relationships through closeness and companionship, with carers taking satisfaction in caring, or fulfilling what they see as the natural role of a parent or spouse.

**Costs** the carer may experience are direct and indirect, financial and social:

- **direct costs** include paying for home alterations, special meals, extra heating, laundry, equipment or clothing, medical care, transport to services, help with household or garden, and paid relief
- **indirect costs** include reduced leisure and personal freedom, a significant impact on intimate relationships and relationships with

other family members, more stress and social isolation, constraints on career opportunities or overtime, having to choose accommodation to suit the needs of the person receiving care rather than one's own preferences, and time taken seeking out appropriate funding and services.

National Health Committee consultation confirms that carers generally take on the job of informal caring because they want to. But it's also been discovered that they often begin caring understanding little of where it might lead and how it might impact on their own **health and lifestyle**. An unexpected finding was the extent to which children and young people care for parents with disabilities.<sup>7</sup> What carers can expect includes:

- more physical work
- **more health problems**, with physical and mental health under increasing strain if the illness, frailty or disability of the person cared for increases; this is particularly the case with older people caring for the very old:
- **physical** health problems related to the type of support provided eg. back problems from caring for someone with physical disabilities; caring is also associated with insomnia, hypertension, heart attacks, exhaustion and weight changes (Opie, 1992).
- **mental** health problems eg. stress and depression, particularly when caring for someone with mental illness. Other factors adversely affecting carers' mental health include being over 60, having meagre social support, being a primary carer, caring for someone with extreme disability, caring for someone with cognitive impairment, caring for a spouse, caring for a male, being isolated, and considering stopping the caring work (Sainsbury, 1997, Abbott & Koopman-Boyden, 1994).



- **more stress** is a commonly reported result of caring, contributed to by:
  - **coping** with the challenging behaviour of the person cared for
  - **worry** over financial and legal matters
  - **concern** about the quality of paid services eg. home support and attendant care

*'Having Dad live with us drastically changed everything about our family life. We had no privacy, there was no let up from the stresses of continual crises.'*

*-a carer's story*

- **fear of what will happen in future** - many carers worried what would happen to the person they cared for once they could no longer care for them, and this was particularly true of parents caring for children with disabilities.
- **fear of what will happen in a crisis** - carers were concerned about: 1) what would happen to the person they cared for if the carer themselves became ill or injured, and said there was no-one else to take on the caring;<sup>8</sup> 2) the availability of services should the person they care for need urgent help.<sup>9</sup>

<sup>7</sup> This is an area where the evidence is anecdotal and further data needs to be gathered.

<sup>8</sup> One carer spoke of organising the household from her hospital bed with a cell phone, after an emergency admission.

<sup>9</sup> Someone who cared for a family member with schizophrenia related being told that even if the person they cared for was in an acute state, they could only be admitted to hospital 'if there was a bed.'

- **having to search and battle** for information and services and money eg. ACC payments, Income Support benefits, equipment, quality respite care, home support.
- **stress** is also experienced by those who have to travel to care for someone
- **less personal freedom and leisure** - the needs of the person who's cared for are usually put before the needs of the carer; carers are with the person needing care for long periods (if not 24 hours a day), and their home lives are disrupted.<sup>10</sup>
- **loss of friendships and support networks** - time and energy demanded by caring can mean carers withdraw from other relationships and lose contact with friends, either because relationships are neglected, or because friends can't cope with people with disabilities. Carers can become overly reliant on the friendship and company of the person they are caring for, and this is one reason carers may be less inclined to want or accept relief, and why older carers sometimes have difficulties when the person they care for no longer needs their care.
- **financial concerns**, both immediate and long-term - some direct and indirect financial costs carers incur have already been mentioned; the following deserve more detail:
  - **employment** - carers may find their ability to earn is reduced, interrupted or stopped altogether; carers in paid employment may compromise career opportunities, be less available for overtime, promotion or training, and work less well because of stress or tiredness; employers may be unsympathetic or unaware of the carer's extra responsibilities and negative about poor performance, time off or reduced hours; carers typically find it difficult to return to the workforce once they no longer need to give care, as if they have been engulfed by the domestic world; paid employment is an important source of income for many carers, a break from caring, and a source of self-esteem and social networks.
  - **financial security and support** - carers often have bigger costs at the same time as they have less earning power, because they tend to subsidise the expenses of the person they are caring for eg. housing alterations and special meals; they also say state assistance is often inadequate to cover the basic needs of the person they care for;<sup>11</sup> carers must sometimes bear treatment costs for health problems as a result of caring eg. physiotherapy for back strain as a result of lifting someone.
  - **long-term financial concerns** - carers say they can't save for the future yet can see government support diminishing; to protect their future investments they often need to pay for legal advice on power of attorney, trusts and asset protection.<sup>12</sup>
  - **accommodation and lifestyle choices** are affected by having to care for someone, with carers needing to move closer to the person they care for, modify their home, or move to one that suits the other's needs. This can limit personal freedom and generate stress for the carer.

*'The house smells ...because of the urinary sheets and dirty nappies around. No matter what I do, I can't seem to get rid of the smell.'*  
(Belgrave & Brown 1997)

Now we have a picture of what it means to be a carer, we'll look at what carers need and what can stop them getting what they need. After that comes a brief discussion of the **barriers carers face** in getting the right services. The final section suggests some strategies for meeting carers' needs.

<sup>10</sup> A carer commented that carers need the freedom to be in their homes without the dependent person being there.

<sup>11</sup> A parent whose full-time work is supporting a child on sickness benefit said that after meeting accommodation and food costs, the benefit left \$60 per week to pay bills and meet all other needs of carer and child, including pharmaceuticals, toiletries, clothing and bus fares.

<sup>12</sup> Legal Resources Trust has produced a video 'Power to Care' explaining The Protection of Personal and Property Rights Act 1988.

## SUPPORT FOR CARERS

### What support do carers need?

What's been written about caring for people with disabilities suggests carers need support in the form of:

practical help

recognition

time away from caring/respice care

financial support

planning.

#### 1. Practical help

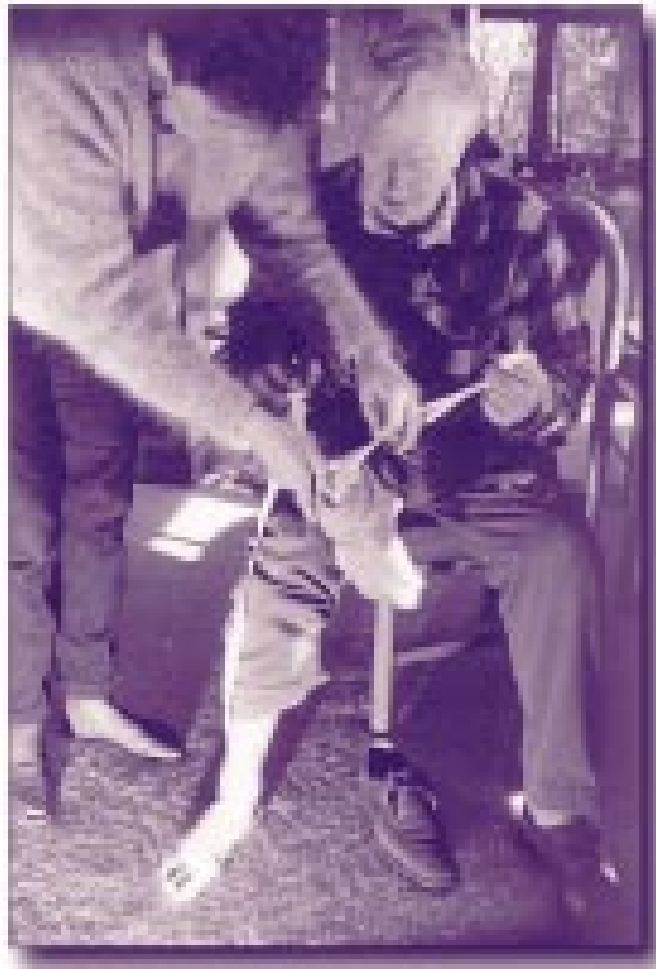
Carers say they need practical help in these areas:

- **physical** - bathing/showering, cooking, feeding, gardening, house maintenance, housework, making financial arrangements, transport
- **emotional** - learning coping skills, problem solving, anger management, dealing with challenging behaviour, negotiation skills
- **practical skills** - learning lifting techniques, using aids, first aid, responding to a medical emergency, learning simple medical skills eg. bandaging, giving injections
- **information** - about how the 'system' works to provide support;<sup>13</sup> also about the illness/disability of the person they care for, and support services available for the carer and the cared for eg. respice care, day care facilities, transport services, financial advice, eligibility for subsidies.

#### 2. Recognition

Carers say they need recognition of caring as an important and often difficult job. Recognition could be given nationally, regionally and in the immediate locality:

- **nationally** - by recognising the contribution carers make to the community; in the UK The Carers (Recognition and Services) Act



1995 was passed, and the Carers National Association set up;<sup>14</sup>

#### In Australia a range of carer support services recognise what carers do and offer early and ongoing support:

- **carer resource centres** are in each state capital under the National Respite for Carers Programme; they have information and advice for carers, including where to go for help of any kind
- **carer respice centres** provide a coordinated system of respice; centres keep up-to-date records of organisations providing respice care
  - **carer payment** is made to people giving substantial personal care or supervision to someone chronically ill, aged and frail, or with a disability; those eligible for payment must:

<sup>13</sup> Various possible sources of improved information were suggested during consultation, including ACC, Health Funding Authority, needs assessment and service coordination services, service providers, NZISS and CHes.

<sup>14</sup> A sign of recognition of carers in the UK and Australia was the first international conference on family care, Caring for Carers, held in May 1998 in London. Jointly organised by the Carers Association of Australia and the Carers National Association (UK), conference agenda items included the economic and social justice cases for supporting carers.

- provide care **in the home** of the person being cared for
- satisfy the pension **income and asset test** (including asset testing of the person being cared for when they are the carer's partner)
- not be receiving **another pension or benefit**

Currently carer payment is made if the person being cared for is:

- over the age of **16 years**<sup>15</sup>
- needing care **permanently** or for at least six months (or less if the condition is terminal)

People eligible for carer payment:

- may **take breaks** from caring to work, study or train for up to 20 hours per week
- are required to take **52 days** a year away from caring.

Australia offers a range of care and support to those **caring for older people**, including a federal government package which expands and improves the Community Aged Care Package; this makes services available to more older people so they can stay in their own homes, and recognises that aging carers often worry what services and accommodation will be available for sons or daughters when they become too frail to do the caring or go into residential care themselves.

Alternative accommodation arrangements for people with a disability in these circumstances are limited. Older carers, particularly those who've been caring full-time for a son or daughter with a severe or a profound disability for 30 years or more, get priority, and it's hoped this initiative will eventually lead into full-time care and support.<sup>16</sup>

- **regionally** - best expressed in the form of available services, GP understanding and community support. Recognition by professional associations and local service providers is important, and providers and consumers see a need for funding and provision of rural services.<sup>17</sup>
- **the immediate locality** - best given by those close to the carer, such as family, friends and neighbours, who can appreciate what the carer does.

Recognising the work and **significance of caring** is likely to mean more emotional and practical support eg. relief, contact with others in similar situations, monitoring of personal stress levels, ability to get involved in other activities, and support for changing relationships, such as between children and parents or spouses.

Carers say recognition and support for their work and commitment makes all the difference to their state of mind and stress levels (Belgrave & Brown, 1997).

Being able to **talk** about the stresses of caring, and coping with the changes it brings is also important. A carer who looks after a head-injured child said at a consultation meeting there should be widespread recognition of those providing lifetime care, and the level of commitment it involves.

*'And it was not until recently that somebody actually asked me how I was. I felt so overwhelmed by the concern shown that I burst into tears, realising then how much stress I was harbouring inside...being able to talk about it to an outside person is so helpful to release some of the pressure we are under. My sister and brother-in-law call me once a month and ask me how I am, how am I coping. It's great to have your efforts recognised'*

*- a carer's story*

<sup>15</sup> From July 1998, carer payment will be available to people caring for a child with a profound disability who is under 16. Those with other than profound disabilities are covered by the Child Disability Allowance.

<sup>16</sup> Press release, Canberra 2 April 1998. Contact assistant secretary, Disability Programs Policy and Planning, tel. 0061 2 6289 8744.

<sup>17</sup> One family intended moving back into town although they had established and modified their home and were running a business from their rural location; their reason for moving was the difficulty of accessing physiotherapy and other services for their son with cerebral palsy.

### 3. Time away from caring/respice care

Time away from caring is critical for carers' physical and mental wellbeing. As we saw before, carers suffer costs and negative effects as a result of providing care. But quality time away can reduce some of them. Key issues are:

- caring can be **physically demanding**, relentless and stressful
- physical exhaustion can be aggravated by **lack of sleep**
- carers have **less opportunity for leisure**, socialising and recreation
- carers living with the person they care for often feel they can **never relax**
- time away from caring gives carers a rest from **responsibility** for someone else's health and wellbeing
- small amounts of **'time out'** from caring make a real difference to carers: 91 percent of respondents in one study wanted to be able to have a break away from caring responsibilities; of these, 61 percent said it was difficult for them to get such a break when they wanted (Lamb & Layzell, 1995).
- carers often have other family members, especially children, who experience considerable stress as a result of the demands on the carer and who need their parent's special attention.

*'If I knew some help was there - say two hours a week so I could get out - I'd cope.'*

*(Belgrave & Brown 1997)*

It's important carers recognise as soon as possible after they begin caring that they'll need **breaks and interests outside the home**. Some carers said during consultation meetings that they found it difficult to contemplate respice care because the person they cared for wouldn't want to go into a



home and they themselves would feel guilty and uncomfortable about it.

It was also clear during consultation that carers have a poor understanding of what **respice care** is available. This is both an information issue and general lack of recognition of carers' work. However, using the available services does involve carers and those cared for being **willing to accept** respice care.

*'To give up everything for another person, regardless of how close that person is, breeds resentment whether it is acknowledged or not. That drains energy. There needs to be time out for recharging without feeling guilty about it. You can then get back home again with a bit more energy to carry on with the task at home.'*

*- a carer's story*

#### 4. Financial support

Carers would welcome financial support because of the direct and indirect costs of caring (see page 14). In **Australia**, carers eligible for payment after income and asset testing have thrived on knowing their efforts are recognised and considered worth supporting.

The problem of **financial inequity** between people eligible for ACC compensation and those with similar impairments not eligible for financial support came up during National Health Committee consultation meetings.<sup>18</sup>

This problem should be addressed at a **national level**. Someone disabled in an accident - rather than by an illness - may be eligible for ACC payments, and these can include payment for carers. So '...people who are injured or disabled through accident have access to more assistance and better services when compared with people with congenital or acquired disability.' (Carter, 1993)

**The issue of paying informal carers** from public funds needs more analysis than we can provide here, but important areas for consideration include:

- the level of **available funding** and how to prioritise carer payment
- current level of use of **respite care services**
- distributing **respite care funding** more fairly
- how to decide **what level of caring** should have state support eg. how many hours a week, or what type of caring eg. supervision, support, household help, and how to distinguish between reciprocity and caring - when does the give and take of normal daily life become caring?
- how to assess **eligibility** eg. would it need income and asset testing; would those getting other benefits be eligible?
- the status and legitimacy of the caring role. Should carers be in a

**contractual relationship** with an agency purchasing their services, or should they be recipients of income support?

- **respite care brokerage**, based on the Australian model (see page 25)

*'I'm really tired most of the time. . . totally shattered. . . I've not had an unbroken night's sleep for 20 years now.'*  
- a carer's story

It's also important to consider whether paying carers would actually benefit them:

- financial compensation might not significantly relieve the **social and psychological pressures** of caring (Arling & McAuley, 1983)
- carers are unlikely to get state support in **real compensation** for the work or opportunity costs associated with caring
- there's a risk existing **support networks** may shrink if people think the carer is being recompensed, and the carer could end up worse off and increasingly isolated (Belgrave & Brown, 1997)
- carers may not want payment or find the idea **offensive** (Belgrave & Brown, 1997)
- finance may not be a major source of carer stress when compared with **emotional factors**, stress and physical exhaustion (Tennstedt & McKinlay, 1989; Sussman, 1976; Cantor, 1980); in two New Zealand studies carers said they would rather have access to better services than payment for caring (Belgrave & Brown, 1997; Opie, 1992).

**An alternative** to paying carers might be to look at fairer and more efficient ways of distributing available resources for:

- **improving information** about available services

<sup>18</sup> These meetings were part of a consultation process resulting in the publication: *Who is responsible for the provision of support services for people with disabilities?* National Health Committee, 1997

- better ways of **prioritising access** to services eg. respite, accommodation, transport, medical services, pharmaceuticals and equipment, to ensure fairness and national consistency.

We remind you of these issues and ask some questions about them in the discussion section of this booklet.

## 5. Planning

Carers often begin caring with little understanding of **where it might lead**. They need support to think about how long they might have to do it, and how intensive it might get as the person they care for becomes more frail, or their illness or disability progresses. Carers need support to work out when it might be better for someone else to take over (Belgrave & Brown, 1997; Opie, 1992; Sainsbury, 1997).

To do this, carers need good information as well as self-awareness and willingness to judge their own **ability to cope** physically and mentally. Levels of care and responsibility often gradually climb with many carers not realising the ever-increasing stress they're under; carers are not always the best judge of how they are coping.

*'Many carers often do not recognise that they have needs themselves. They are so busy attending to other people's needs that they suppress their own.'*  
(Lungley, 1995)

Carers need to know what **options** there are for looking after the person needing care, and how to choose quality support services or resthome care for them.<sup>19</sup> Carers must be aware of available support services. Many organisations produce pamphlets and offer field worker services which have reduced the burden of caring over the years.

Carers might need support to plan what level of care is needed, and how



this fits in with what they have decided they can offer. Some carers might find **counselling** helps them move from primary carer to a less intensive role (Sainsbury, 1997; Opie, 1992).

If they continue providing care beyond their coping ability, carers **risk** their own health and wellbeing, as well as that of the person they care for.

*'... the amount of personal stress and hardship can affect the quality of care given ... the potential is real for the informal care situation to deteriorate into elder abuse and more family violence.'*  
(Belgrave & Brown, 1997)

As we've pointed out before, carers also need support to plan for the time when they no longer have to provide care.<sup>20</sup>

<sup>19</sup> eg. NZ Home Support Association is developing a consumer pamphlet on choosing quality home support services.

<sup>20</sup> Someone who cared for a family member with multiple sclerosis said being a carer was her job, and that if it were to end, she would be lost. The same carer noted she was ineligible for retraining to enter the workforce, but that the family member she cared for was eligible for training help that would never be applied in the workforce.

## What stops carers getting the support they need?

As we've seen, carers may lose **social contact** as relationships are neglected, or friends can't cope with people with disabilities, and they may become too reliant on the friendship and company of the person they are caring for. This could be why some carers are reluctant to accept relief.

**Lack of recognition** for what carers do might be an even more significant reason caring issues have remained so long behind closed doors. Paying eligible Australian carers has encouraged them to use available services, including their 52 days a year respite care.

In **New Zealand** we have to look not only at how many respite care services are available but how suitable they are for medically fragile people with disabilities, particularly children. Other hindrances to support for carers are:

- **Needs assessment** - carers often provide care for several years before seeking help. Carers must first recognise themselves as being carers and secondly, must be identified as carers by whoever assesses needs for services and coordinates access to them. In New Zealand, we should be paying attention to the needs of the carer at the same time as the person with a disability is being assessed.
- **Difficulty accessing information** - as we've seen, carers often struggle to find out about many aspects of providing care and what services and support are available. Information tends to be 'discovered' through informal networks and support groups. Access to specific information and support groups is also difficult for carers of people with dual or multiple diagnoses as these tend not to fit into existing categories.
- **Self perception** - carers may suffer guilt and low self-esteem, characteristics likely to prevent them seeking services.
- **The person needing care** - may not accept or recognise their impairment, leading to resentment, misunderstanding and guilt if the carer wants to get help. The person may also fear the carer will discuss their personal details in a support group, and this can contribute to carer guilt too.
- **Isolation** - without good social networks, carers can end up feeling more and more isolated and stressed, with few opportunities to establish new friendships (Opie, 1992).
- **Culturally appropriate support services** - inappropriate services prevent Maori carers accessing support. Many carers for whom English is a second language also find accessing services and information difficult (Ratima, Durie et al, 1995).
- **Financial concerns** - carers may be reluctant to seek services if they think these might cost money. This is particularly so with respite care, when the carer may feel they should leave the house if someone else is coming in but can't afford to go on holiday.
- **Provision of adequate services** - poor services are an immediate and obvious barrier to supporting carers. There must be enough services of the right sort and quality. During consultation, some carers said they knew respite care was available and had tried to get it. They found it limited by the number of people able to provide it and in the case of mental illness, by the illness of the person needing care.

## STRATEGIES FOR MEETING CARERS' NEEDS

Research on carers has consistently found they get **too little support** for their work. It also identifies areas where support would help carers continue to care without risking their own health or that of the person they care for.

This section has some suggestions for translating carers' needs into **strategies**. We will be looking for confirmation that these strategies are relevant and likely to be useful in the discussion we hope this booklet prompts. We restate the strategies in the discussion section in the front of this booklet and ask for comment.

### Information

Carers consistently say information is **hard to come by**. They say 'we don't know what we don't know' because they can't look for information on something they don't know exists. Carers need information on:

- the **likely progression** of the condition of the person they're caring for
- the **likely behaviour** of the person they're caring for eg. someone home from hospital after a head injury may behave quite differently than they did before the injury; the person with dementia will have many challenging behaviours
- how to cope with **challenging behaviour**
- how to cope with any **medical and/or personal needs** the person has eg. how to bath or shower someone, use a wheelchair or a commode, or give medication
- what **support services** are locally available eg. respite care, meals on wheels, transport services, communication aids
- what **financial support** is available through ACC and/or NZISS
- what **further education** or training opportunities may be useful and are available

- what **support groups** are available locally and nationally; these often have information packs relevant to the disability they cater for.
- any legal issues they may have to deal with.
- Freely available **carer information packs** may be a useful way of distributing this information.<sup>21</sup> They could be made available through:
  - **health services**, including GPs, pharmacies and outpatient clinics, and be part of hospitals' discharge protocol
  - **income support service** and employment service offices.

Information packs wouldn't have to contain all the above information, but should tell carers where to get it. The **UK National Carers Association** publishes a list of all the information pamphlets it has and carers tick what they'd like to receive free of charge. Information is available in several languages, on cassette and in large print.

**Service planning** and provision needs better information collection and analysis, as well as better ways of monitoring and reviewing services.

### Discharge planning

People admitted to **hospital** for reasons directly related to their disability should be able to plan for their future during their hospital stay and on discharge. Carers should be included in this process and be given information and guidelines on what to expect when the person they care for comes home. Discharge planning should involve:

- providing an **information pack** (described above)
- appointing a **care coordinator**
- discussing any **home alterations** needed to fittings or structure in plenty of time

<sup>21</sup> Mosgiel Abilities Resource Centre has developed a Carers Resource Kit. HFA North is supporting the formation of Carers New Zealand, a national network of carers. This organisation is developing a carers 'Survival Kit.'

Image removed

- detailed and realistic discussion of the likely **course of events** for the person with a disability and their carer
- discussing **‘where to from here?’**, telling the family about future out-patient and GP appointments, visits from the district nurse, social worker etc
- initial development of a **crisis plan** - what if the carer can no longer provide support because of illness or accident?

### Needs assessment

Carers’ needs should be assessed at the same time as the needs of the person they are caring for. This should include:

- **stress factors** on the carer, including current and potential physical, emotional or financial risk
- carer awareness of available carer **support services**
- **carer willingness** to use respite care services.

**In the UK**, carers are entitled to assessment under The Carers’ (Recognition and Services) Act (UK) 1995. The Act’s Practice Guidelines require these points to be

taken into account when assessing carers:

- their **perception** of the situation
- the nature of their **relationship** with the person with a disability
- **tasks** to be undertaken and their impact
- their **social contacts** and the support they get from family, friends and neighbours
- their emotional, mental and physical **health**
- their **willingness** and/or ability to provide care, and the options available, particularly for carers in employment
- their **understanding** of the person’s illness or disability, and its likely/possible development
- **other responsibilities** eg. work, education, family/childcare commitments
- the carer’s **strengths** and ways of coping.

Carers at consultation meetings were concerned that assessment was done in their absence. This sometimes meant the disabled person was assessed as being more capable than

they actually were, and was a particular problem for head injured people.

#### Carers called for:

- needs assessment which includes the carer and use of **integrated care packages**
- opportunity to **appeal** an assessment.

## Service development, access and better delivery

The Health Funding Authority (HFA) funds services which give carers **time-out** (known as carer relief or respite care). These have been criticised for offering relief on the basis of the disability of the person being cared for, rather than on the carer's needs (Lungley et al, 1995). This should change as funders and providers focus on the needs of both carer and cared for.

#### Suggestions by carers and those they care for about respite care which would suit them better include:

- funding and providing readily available carer relief for **crisis management** 24 hours a day, seven days a week
- funding and providing **in-home carer relief**
- funding and providing **short, frequent carer relief** eg. a few hours a week
- improving **national consistency** of carer relief services.

Carers say their needs would be better met by provision of these well organised and well coordinated services including:

- emotional support/**counselling** at the outset of caring
- **culturally appropriate** services
- staff **continuity**
- well trained, well informed and effective **case managers**

- improved needs **assessment**
- individualised care **programmes**
- stable **eligibility** criteria (and reduction of time-consuming form filling).

When it comes to financial support, carers would like more **openness** about available benefits and ways of accessing them.

#### Possible strategies are:

- ensuring fully explanatory and easy-to-find **information**
- establishing carer support **brokerage services**,<sup>22</sup> including packages of respite care, home support and attendant care.<sup>23</sup> Brokers would be responsible for budget holding, using funds from all available sources, and would assess eligibility and level of support need.<sup>24</sup>

## Better relationships between carers and health professionals

Many carers say they don't get the support, recognition and information from health and disability sector professionals they need. But appropriate support services won't be developed until service providers recognise that carers are:

- **co-clients** who have their own needs
- **co-workers** who should be consulted, listened to and supported (Twigg & Atkin, 1994; Belgrave & Brown, 1997; Jordan, 1990).

Carers say doctors often don't seem to know what services are available or value carers' input. As health sector '**gatekeepers**', it's vital that primary health care professionals are aware of carers' needs and the services available to them. Strategies include:

- enhancing **recognition** of carers in the community
- **training** health professionals to listen to carers

<sup>22</sup> Brokers could follow the Australian model of a separate provider group of respite care brokers, or they could be the same people as service coordinators, fully trained in brokerage, care coordination and integrated care.

<sup>23</sup> Home support and attendant care are terms currently used by the Health Funding Authority to refer to household care and nursing care respectively.

<sup>24</sup> 'Level of support need' requires definition by the Health Funding Authority, and should have priority access criteria built in.

- **preparation** for health professionals to include carers in service delivery for people with disabilities.

If health and disability sector professionals focused more on carers as clients and co-workers it would incur no financial risk and have these

**benefits:**

- early identification of potential or actual carer stress, enabling **stress prevention** or reduction
- development of **better services** for carers as a result of carer input in service configuration, designing services that meet carers' needs, and letting them do their work longer
- **recognition of abuse** and **neglect**
- **better access to ACC**, NZISS and DSW information, and better and fairer access to available funding and benefits, reducing carer stress by reducing the amount of battling they have to do.

## Training for carers

Carers believe training programmes should cover:

- **basic skills** of providing care eg. lifting techniques, first aid, bandaging
- **copng skills** eg. problem solving, anger management, dealing with challenging behaviours, negotiation.

Some carers have already attended courses run by the Red Cross and St John's Ambulance Service. Existing resources like these should be developed, with transport assistance if needed, so carers can attend courses.

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<sup>25</sup> This publication was produced in tandem with Richmond, D.E. and Northey, R., (1997) "Home is Where the Heart Is" North Health and Waitemata Health

## NOTES

