

# findings

THE STEGLEY FOUNDATION

## Improving the lives of people with chronic illness

by Christine Walker

There is an urgent need for the Federal Government to recognise the disadvantages faced by people with a chronic illness, and to research the outcomes of providing a concession card based on their needs.

The current income-related concession card system limits people with chronic illness to managing their existence rather than participating fully in society. It also deters a considerable number from working. This edition of *findings* summarises the results that were published in the report *A Concession Card for People with Chronic Illness*.

Peter is a young man with cystic fibrosis who spends most of his Disability Support Allowance on multiple prescription medications to keep him alive. If he worked full time and grossed more than \$13,280 a year, he would lose his entitlement to pharmaceutical concessions.

*"I find that the prospect of losing my Health Care Card entitlements, particularly the pharmaceutical concessions, is a significant deterrent to my seeking gainful employment. It is an unwelcome burden on my finances at a time when I am supposed to be making use of every available opportunity to contribute to society – a burden that very, very few other people are forced to endure."*

### Key findings

The results of this report on a needs-based concession card for people with chronic illness show that:

- If people with chronic illness have a concession card based on their needs, it will help them optimise their health and contribute more actively to their communities.
- A cost-benefit analysis of providing a needs-based concession card will demonstrate that there are significant savings for the community by enabling people with chronic illness to live their lives more fully – potentially as employees in the paid workforce, studying or retraining, or contributing to the community in other ways.
- Chronic illness is a growing cost to those people who experience it and the community as a whole.
- People with chronic illness face extensive and ongoing financial costs. These include the range of medical, allied health and community support services they require.
- Because of these costs, people with chronic illness are often forced to adopt strategies to 'make ends meet', and these are often detrimental to their health.
- Further research is urgently needed to determine how individuals with chronic illness and the community can benefit from a needs-based concession card. ►►

### Background

This report is based on the work of the Pharmaceutical Benefits Scheme and Health Care Card (PBSHCC) Working Party of the Chronic Illness Alliance, and was conducted on behalf of the Chronic Illness Alliance. The Working Party ran forums to gauge members' level of concern around the costs of caring for someone with a chronic illness.

Forum participants called for a Concession Card for People with Chronic Illness and then undertook to explore the proposal more fully.

This report contains case studies which examine the costs and the impact of chronic illness on people's lives.

### The cost of health care for people with chronic illness

The ability of people with chronic illness to access the health services and medicines they need is not

Once people who are well have paid for housing, food and essential services, they may have up to 50% of their income to spend on entertainment, education, travel or whatever they choose.

However, once people with a chronic illness have paid for essentials and the health and support services they need, they often have only 10% or less of their income left...and this is a lifelong situation.

ensured. Their disposable income is substantially reduced by the costs associated with maintaining their health.

They are likely to restrict their expenditure on energy costs, transport and telephone services in order to afford medications.

At the same time however, because of their illness, they are more likely to need such services. Largely due to the extra costs they face, people with chronic illness find it exceedingly difficult to afford their own homes.

### Why concession cards exist

The Government believes that concessions play an important role in the welfare system. They are designed as an income supplement to allow 'all Australians to use essential health care services and to maintain social living standards by ensuring access to electricity, heating, transport and telephone services, as well as encouraging or maintaining home ownership'.

With the introduction of Medicare in 1984, a concession card was not needed for free hospital treatment but was required for dental and hearing services, as well as the PBS concessions. This card also became the means to identify a person's eligibility for transport concessions.

Later this card identified the people eligible for further state and local government concessions. Access to these benefits varied with the type of card, as well as between states.

### How people with chronic illness manage their living

In 1997 the Chronic Illness Alliance published a *Survey of Costs to People with Chronic Illness*

*Who Do Not Have a Health Care Card*. It found that:

- There are people with chronic illness who work and have good incomes, but their disposable income is considerably reduced because of expenses associated with their illness.
- Many people, whether on good incomes or on benefits, are forced to adopt strategies in order to live within their circumstances. This can mean restricting their use of gas and

**Penny is a young woman with cystic fibrosis, who works for a monthly wage of around: \$1,250**

She is not eligible for a concession card and her illness-related costs are: **\$321.60**

If she had access to a concession card her monthly costs would be: **\$115.30**

This is a difference of: **\$206.30 per month**

She also has 'one-off' equipment cost of: **\$754**

Because this young woman does not have a concession card she spends 25% of her monthly wage on staying alive.

electricity, or going without food or clothing.

- It is common for families to go without allied health services in order to afford medication, or to halve their prescribed amount of medication to make it last longer. Some families share medication. It is not uncommon for parents to forego caring for their own health in order to pay for their children's health. Most often, families go without entertainment, holidays or respite.
- Concern about losing their concession card discourages some people from working. This is especially the case for those who are only able to work in low-paid positions or who are only able to work for limited periods.
- An unknown number of people with chronic illness work 'cash in hand' in order to retain their concession card and accommodate the episodic nature of their illness. Anecdotal evidence suggests they are exploited. It also costs the community as a whole, since the Commonwealth forgoes the tax on these earnings.
- When determining eligibility for the Concession Card (which is currently based on income), the costs associated with maximising a person's health or providing prophylactic care are not taken into account.
- The consequence of this situation is that an unknown proportion of people with chronic illness live unnecessarily in extreme poverty. They cannot get the most benefit out of their lives, nor does the community. ►►

### The impact of chronic illness on a family

**The Jones family is made up of father Harold, mother Fiona, and three children. All members of the family have a chronic illness. The illnesses are epilepsy, sleep apnoea, asthma and chronic depression. The epilepsy is controlled mostly with medication; the apnoea is controlled with a machine; the asthma requires control with both medication and a nebuliser, while the chronic depression requires medication.**

While most families with three children would find the cost of living expensive, this family has significant additional demands on their income. It is a single income family, with the mother unable to work because of her caring responsibilities.

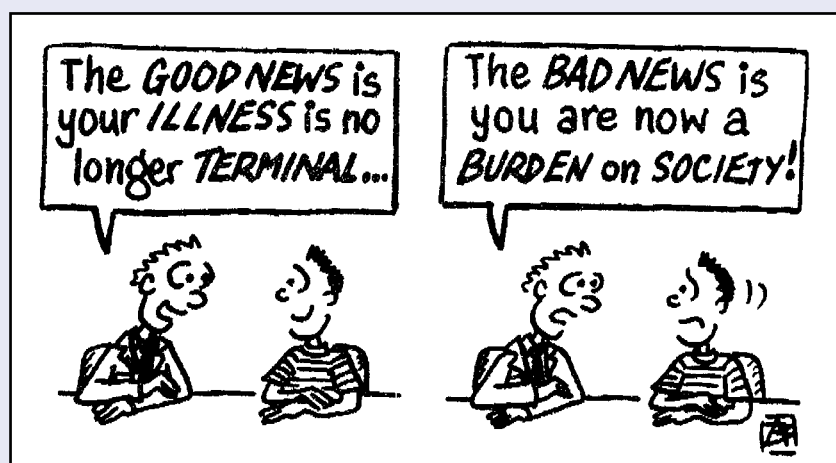
The children are on Child Disability Allowance so they receive the Health Care Card, although the adults do not have a card. The children's medication has a surcharge of \$4.20 per script. The father uses the same medication as one of the children, so to make ends meet the script for him is put through in the child's name.

The substantial chemist's bill is up to \$100 per visit, but it still does not reach the Safety Net limit as many of the medications are not on the Pharmaceutical Benefits Scheme. The adults do not qualify for the Safety Net limit until they have spent \$600. Each child must spend half of that to qualify for the Safety Net in his own right.

The illnesses mean that food is more expensive because it is not always possible to buy generic brands. Food labels must be checked for additives to which the family is allergic. Clothing is an additional expense because the family's allergies mean it is not possible to buy the cheaper man-made fibres. For the same reason, household items such as beds, linen, floor coverings, curtains and furniture must be researched before purchasing.

Safety is a priority over lower costs in all matters. Household renovations must take into account the safety requirements of family members who have seizures. For example, temperature limiters on hot water systems are necessary in the event of a seizure. Energy costs are also increased due to illness; there is the cost of running a machine to monitor for sleep apnoea and the house must be kept warm and dry during winter to help those family members with asthma. A clothes dryer is necessary to ensure clothing is not damp.

Cars must be kept in good running order in case of an emergency visit to the general practitioner, specialist or hospital.



CARTOON: BEV AISBETT

### **Making the case for a needs-based concession card**

Access to a Concession Card must be based on the needs of a person with a chronic illness to live at an optimal level. Eligibility may be determined by the general practitioner working with the patient, by a specialist medical practitioner or an allied health professional specialising in the field of the patient's condition.

However since the aim of the Concession Card for People with Chronic Illness is also to produce good outcomes for the family and the consumer, eligibility cannot be based purely on medical criteria.

Currently, provision of the Child Disability Allowance is based on a child's ability to function at various stages of social development. Some aspects of this approach can be emulated when determining eligibility for a Concession Card for People with Chronic Illness. This means that eligibility would be partly determined by the extent of people's needs as it relates to their ability to function well in their community.

## **Key Recommendations of the Chronic Illness Alliance**

The Alliance recommends that the Federal Government:

1. Commissions research into the numbers of people with a chronic illness who are able to, but do not work because they fear losing their Health Care Card; and the numbers who do work, but have much of their income swallowed up because they pay full price for their health care.
2. Carries out research to measure the favourable outcomes that may result from providing a Concession Card for People with Chronic Illness.
3. Explores the feasibility of a Concession Card for People with Chronic Illness, basing future aid on the total level of costs they face.
4. Assists the Chronic Illness Alliance to continue its research into the needs of people with chronic illness, their families and carers to ensure they maintain an optimal level of health.

### **Further information**

The Chronic Illness Alliance represents more than 40 consumer and advocacy groups on policy matters of common concern. Further information and copies of the full report are available from the Alliance on 03 9479 5827 or 9479 3218.

## **The findings summaries**

The Stegley Foundation is a private philanthropic trust which supports community organisations working to challenge discriminatory policy and practice, build social infrastructure and promote social justice and equity. One way in which it does this is by publishing material which can be used by many communities and organisations fighting for policy reform and progressive social change. These **findings** documents summarise the material so that it is more readily accessible to decision-makers, policy developers, the media and the broader community.

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