

# The Carers' Charter



“The system at the moment is trying to put oil on a moving wheel. They need to fix the wheels instead of trying to patch things up.”

1

A Carers' Bill should be developed for Northern Ireland, similar to that enacted in England in 2014 and expected to become law in Scotland in 2017.

3

Each HSC Trust should coordinate a Carer Strategy for their area in conjunction with other relevant government agencies, third sector agencies and carer representatives. This should be updated annually and contain (in accessible formats) information about the services and supports available and their contact details.

5

Within the HSC Trusts' learning disability programmes of care, an existing senior staff member should be named as champion for carers. This officer would produce an annual report to the HSC Trust Board identifying the service supports provided to carers and the extent of unmet need.

2

Government Departments and other agencies must work together to ease the burden on carers. There should be one primary point of contact for carers when dealing with statutory agencies. Support planning should be person-centred.

4

There should be a regional electronic register to identify the number of family carers and (adult) people with a learning disability in Northern Ireland and their assessed needs for support, compiled with carers' input to ensure accuracy of information. This could be held by HSC Trusts but shared with other Departments (with appropriate safeguards and permissions) to assist their planning and detail their responsibilities (under the new Act).

6

Health and social care staff should be appropriately trained and resourced to recognise and meet the needs of carers and their loved ones. Similar training should be provided in other agencies that have frequent contact with family carers.

7

All carers should have a simplified and more streamlined Carers' Assessment of their needs by HSC Trusts which is reviewed annually and implemented fully.

9

Care and support planning should be person centred and should include emergency and futures planning. It should involve the person cared for, the primary carers, and wider family and friendship circle. A written copy of this Plan should be shared with all relevant parties. This should be reviewed annually.

11

HSC Trusts should expand the range of carer support services they currently provide, such as short breaks / respite and home-based supports. The present variation in the availability of these services and the resources devoted to them needs to be addressed.

8

Paperwork and the number of forms should be reduced and simplified with information shared with appropriate safeguards across HSC personnel.

10

Carers and families should have access to education, training, counselling and information at times to suit them. In addition, publicly funded carer support groups should be developed to ease people's isolation. (This could include the use of social media and other technological solutions especially for carers in rural areas.)

12

Greater support should be provided to carers to enable them to avail of Direct Payments /Self-Directed Support. Greater consistency is needed across HSC Trusts on the availability of Direct Payments / Self-Directed Support and hourly rates paid under them.

# Lonely. Anxious. Exhausted. And helping to save the Government a fortune.

The case for a Charter for Lifelong Carers in Northern Ireland.



# Facing Reality

Many people with a learning disability require life-long care and support. In Northern Ireland most of that care is provided by family members.



Northern Ireland has a higher proportion of people with a learning disability living in the family home and cared for by an ageing family member than anywhere else in the UK or Ireland.

Many older carers of loved ones with a learning disability have looked after them for more than 50 years. They are now into their 80s and 90s.

Many care 24 hours a day, 365 days a year with few or no breaks.

Our 'Careful Plans' Report (2010) found that the majority of older carers described their caring duties as 'non-stop'. They also feel isolated and have physical health problems and emotional stress associated with caring.

On top of their caring duties, carers have to cope with an avalanche of paperwork and bureaucracy, much of which they do not understand. As a result, benefits and support are going unclaimed.

It costs the state more than £30,000 per year for a person to live in a nursing home. Those needing specialist care can cost in excess of £150,000 per annum. Carers receive a tiny fraction of this in social security benefits and support services.

Many older carers of people with a learning disability fear for what will happen to their loved ones when they die.



*"A Carers' Assessment is useless. Once it's done, it's just put on a shelf to gather dust."*

## Carers in Crisis

Carers are not looking for sympathy. What they want is access to support and some recognition of the important role they play in society. Yet too often they feel like forgotten people - isolated, anxious and battling against the machinery of bureaucracy, which seems weighted against them.

Here are some of the comments we've heard from carers.

"I was very despondent about what lay ahead for (my son). I was worried that if anything happened to me he would end up in residential care. People are shocked when I say it, but we wished he would die before us."

"Health and social service staff have no idea what my daughter needs, and they have no time to find out."

"Society's attitude needs to change. When I told somebody recently that I was a retired teacher and a full time carer, his eyes glazed over and he switched off. We're invisible."

"The system needs to be simplified."

"Information should be clearer."

"The system at the moment is trying to put oil on a moving wheel. They need to fix the wheels instead of trying to patch things up."

"A Carers' Assessment is useless. Once it's done, it's just put on a shelf to gather dust."

Organisations like Positive Futures do their best to support carers, but they can never do enough. All over Northern Ireland there are families we haven't yet reached, and in many cases they are coping alone.

## The Case For a Carers' Charter

It's time that the rights of lifelong carers are enshrined in a Charter that decision makers, planners, commissioners and service providers should sign up to.

This Charter should form the basis for a revised Carer's Act for Northern Ireland similar to that enacted in England in 2014 and expected to become law in Scotland in 2017.

*The Carers' Charter (set out overleaf) addresses issues such as:*

- Simplification of paperwork and assessments
- Ease of contact with Health and Social Services
- Joined-up Government, so that Departments work together
- Older carers getting the right support at the right time

For too long, society has paid lip service to the value of carers, without making any appreciable difference to their situation or wellbeing. The Carers' Charter is a bold endeavour to change that.

All we're asking is that lifelong carers are recognised for the valuable contribution they make to society and that they don't have to battle "the system" on top of dealing with the needs of their loved ones.

### Find us on Twitter and Facebook

Mention us to your friends – the more followers we have on social media, the more we can spread the word about the services we offer for the people we support and the good news about the difference we are making to the people we support and their families across Northern Ireland.

### Join the conversation:

If you have a Twitter account, you can follow us @PFTweets or find us at [twitter.com/PFTweets](https://twitter.com/PFTweets)

Or find us on Facebook: [facebook.com/positivefutures95](https://facebook.com/positivefutures95)

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