

Newcastle Carers Strategy

'Your Views Count'

A survey of carers' experiences and views of information for carers in Newcastle

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1. Background

The Newcastle Carers Strategy 2005 – 2008 sets out a vision for services in the future and an action plan for change. The strategy provides a framework within which all agencies can provide quality services for local carers. It aims to build upon current good practice and to make the necessary changes to improve services.

As part of the plan to improve services, seven sub-groups were established, each to focus on a different aspect of carers' need. Our group, the 'To be fully informed sub-group', was charged with improving information for carers in Newcastle in a number of target areas, encompassed within the following quality standard:

“Any service providing information to carers, gives information that is comprehensive, accurate, appropriate, accessible and responsive to carers’ needs”.

1.1 The 'To be fully informed sub-group'

Our group includes representatives from: The Alzheimer's Society, Carers Centre Newcastle, Contact a Family North East, Newcastle Hospitals NHS Trust, Northumberland Tyne and Wear NHS Trust, PROPS as a partner of Safe Newcastle, Saville Medical Practice and the Newcastle Community Stroke Service. A full list of members can be found in Appendix one.

1.2 Purpose

One of the targets that the Carers Strategy set our group, was to investigate how information for carers is distributed and where it is currently available in the City. As a result, we carried out a large scale postal survey of carers in 2006 to provide information on the following:

- how well is information distributed?
- where is it available?
- what type of information do carers find useful?

This report provides a summary of the results of that survey plus recommendations for local service providers on how to improve their information-giving to carers.

1.3 The Survey

A questionnaire was circulated to 2,073 carers across Newcastle in the summer of 2006 with a return of 432 completed questionnaires.

Each organisation represented on the sub-group took responsibility for distributing the survey to carers whom they had contact with. This

ensured that the survey went to a wide and varied group of carers, including stroke carers, dementia carers, parent carers and carers of people with drug and alcohol problems.

2. Results

This report provides an overview of the results of the survey with relevant recommendations. A full copy of the results are available on request from Alex Martin, Carers Centre Newcastle, 6 Saville Place, Newcastle upon Tyne NE1 8DQ, telephone 0191 260 3030.

2.1 About the respondents

- 73% of the carers who took part in the survey were female and 24% male.
- 86% were the main carer for the person(s) they cared for.
- Carers ranged in age from 18 to 65. Of all those who responded, 79% (336) were aged 45 or over; 43% of that number were aged over 65. The least common age group represented in the survey was 18 to 34 (5%/20).
- When asked how many years' people had been in a caring role for: 27% (113) said between one and three years, 25% (108) between four and seven years; 43% (184) for eight years or more with 40% (74) of that number having been a carer for 16 or more years.
- The typical respondent who took part in the survey was female, aged 65 or over who had been a carer for between 8 and 16 years.

2.2. Do you find it easy to get hold of relevant information to help you in your caring role?

The majority (70% (301)) of carers said that they found it easy to get hold of relevant information to help them in their caring role. Of those who found it difficult, typical comments included:

“It's difficult to find information, there are so many sources and it can be confusing and conflicting.”

“I find I have to pro-actively seek relevant information through a variety of sources.”

“No one has ever approached me to tell me where I go for information.”

“I find it very difficult as I don't know what is available and therefore don't know what to ask for, or where to go.”

“Yes, but hard to get the right information.”

“There is almost too much information and it would be easier to have one person to help co-ordinate all services used by very disabled person.”

2.3 Where do you get information?

Carers get information from a variety of places in their local community. The most frequently mentioned locations were:

Organisation	no.	%
Newcastle Carer Centre	192	44%
Social Services	173	41%
Other voluntary organisations	169	40%
GP Surgery	165	39%
Other health professionals	138	33%

Some carers commended specific groups for the information they provide, in particular: the Alzheimer's Society, Contact a Family, the Newcastle Stroke Team and the Shaw Trust. A small number said that they found their Local Library (11%) and the Internet (20%) to be good sources of information.

2.4 What kinds of information do you use?

The research revealed that carers use a wide range of information; the most popular are listed in the following table and show information about state benefits to be the most common type of information that carers use. In this study, carers were least likely to seek out information on employment matters (7%) and childcare (6%).

What kinds of information do you use?

Type of information	no.	%
Benefits	260	61%
Health issues	212	49%
Support Groups	185	44%
Rights for carers	169	40%
Medication	161	38%
Coping strategies	129	30%
Home care	129	30%
Short Breaks	102	24%
Financial and Legal	87	20%

2.5 What format do you prefer information to be in?

82% (345) of carers said that they prefer written information, followed by 70% (298) whose preference is for information delivered through face-to-face contact. Less prefer electronic information (email: 11% plus the internet: 14%), while a small number prefer information on tape (2%). The findings indicate that the greatest preference is for written information with one-to-one contact (face-to-face by telephone or email) rather than from an anonymous source.

“I found leaflets also useful but 2nd to face-to-face talk.”

“Things that are important to me for communication - bold, large print - information that is easy to understand in no more than 3 sentences - an indication as to where additional information can be found if needed - preferably by speaking by telephone.”

2.6 Which public places do you think should have information for carers?

The most important places that carers thought there should be information for them were:

Type of information	no.	%
Post Office	319	75%
Supermarkets	257	60%
Bus stops	196	46%
Banks	127	30%

Some carers simply felt that information for carers should be everywhere, while others listed a range of venues, including: billboards, Council buildings, places of social interaction e.g. churches and working men's clubs.

"Sharing information is of prime importance, perhaps use of ladies toilets, powder rooms, restaurants etc and all places used by the public, it should be prominently displayed."

2.7 What piece of information have you found most useful?

The answers to this question compliment those given in response to the question 'What kinds of information do you use?' (see 2.4 above). In both cases, carers reported that financial information (most commonly concerning benefits) was the type of information that they find most useful.

"Information about your rights. Such a vague area - people on Income Support do not realise that being a carer can mean more money for them."

After financial matters, carers find information from and concerning voluntary organisations to be the most useful, followed by practical services provided by the statutory sector (primarily Social Services).

"What voluntary organisations to go to in regard to disability issues. You need the right information or to be directed to other organisations who can provide it."

"Eventually when a social worker came to our aid - helped with how to get loan equipment and a sitter."

2.8 What piece of information have you found least useful?

Many carers used this question to express their belief that all information was useful.

"I think all info is useful. It means you are informed about everything and even if it isn't beneficial to you, you can take it in and pass on to other carers who may need it. It's amazing how many people don't know what's out there to help them. I was one of those people."

Where people did express dissatisfaction with information it was most often with the manner in which information was communicated,

in particular, verbosity, jargon, technical language, complicated forms, and the increasing trend in providing information electronically.

"Internet can be frightening and misleading, often gives information but does not always tell you what to do about it - particularly on a local level."

3. Summary

The survey undertaken by the 'To be fully informed sub-group' tells us that some carers are able to access information in a variety of places across the city; Newcastle Carers Centre being a key point of contact along with a range of other voluntary organisations and health care providers.

However, the results also show that carers can experience difficulties in accessing information, in particular, that there is too much information that is badly presented and that there is no-one to talk it through with. Carers commented that workers who provide them with information are not always sensitive to their needs and don't take the time to explain the information they are giving.

The results showed that 70% of people who said they found it easy to access information were most likely to seek out information about benefits, health issues and support groups. People were less likely to seek out information about employment or childcare. This could be more a reflection of the age range of the people who responded.

Carers like written information that is clear and jargon free. Most importantly they want the opportunity to talk to someone face-to-face or over the telephone, a small number are using e-mail.

When asked where else they would like to see information, the Post Office and Supermarket were the favourites, although carers would like to see information made available in a wide variety of places.

The findings from this survey show that the carers who took part were mainly older, female and had been in a caring role for a number of years, suggesting that access to information remains very important throughout their years of being a carer.

4. Recommendations

- Greater co-ordination between information providers would reduce duplication and improve access to information for carers.
- The content of any carers' information should take into consideration the kinds of information they find most useful i.e. benefits, support groups and health issues.
- Information for carers should be clear, easy to read and follow accessible information guidelines. Wherever possible, carers should be given the option to receive information face-to-face.
- Information for carers should be accessible in public places, in particular, Post Offices, Supermarkets and Bus Stops.

Appendix 1

Members of Newcastle Carers Strategy 'To be fully informed' sub-group

George Chambers, Carer

Sarah Lewis, Information Officer, Contact A Family

Alex Martin, Information Co-ordinator, Carers Centre Newcastle

Caroline McGarry, Patient, Carer & Public Information Co-ordinator, Newcastle Hospitals NHS Trust

Karen O'Rourke, Patient Information Centre Co-ordinator, Northumberland, Tyne and Wear NHS Trust

Pru Picard, Liaison Social Worker, Newcastle Social Services

Pam Richold, Trust Quality Officer, Northumberland, Tyne and Wear NHS Trust

Gail Robson, Service Manager, PROPS 'in partnership with Safe Newcastle'

Jane Walker, Stroke Services Information Co-ordinator, Newcastle Community Stroke Services

Trevor Watson, Information Officer, Alzheimer's Society – Newcastle

Meg Woollam, Customer Services & Marketing Manager, Newcastle Social Services

Thankyou...

We would like to thank all the carers who so kindly gave their time to take part in this survey.

