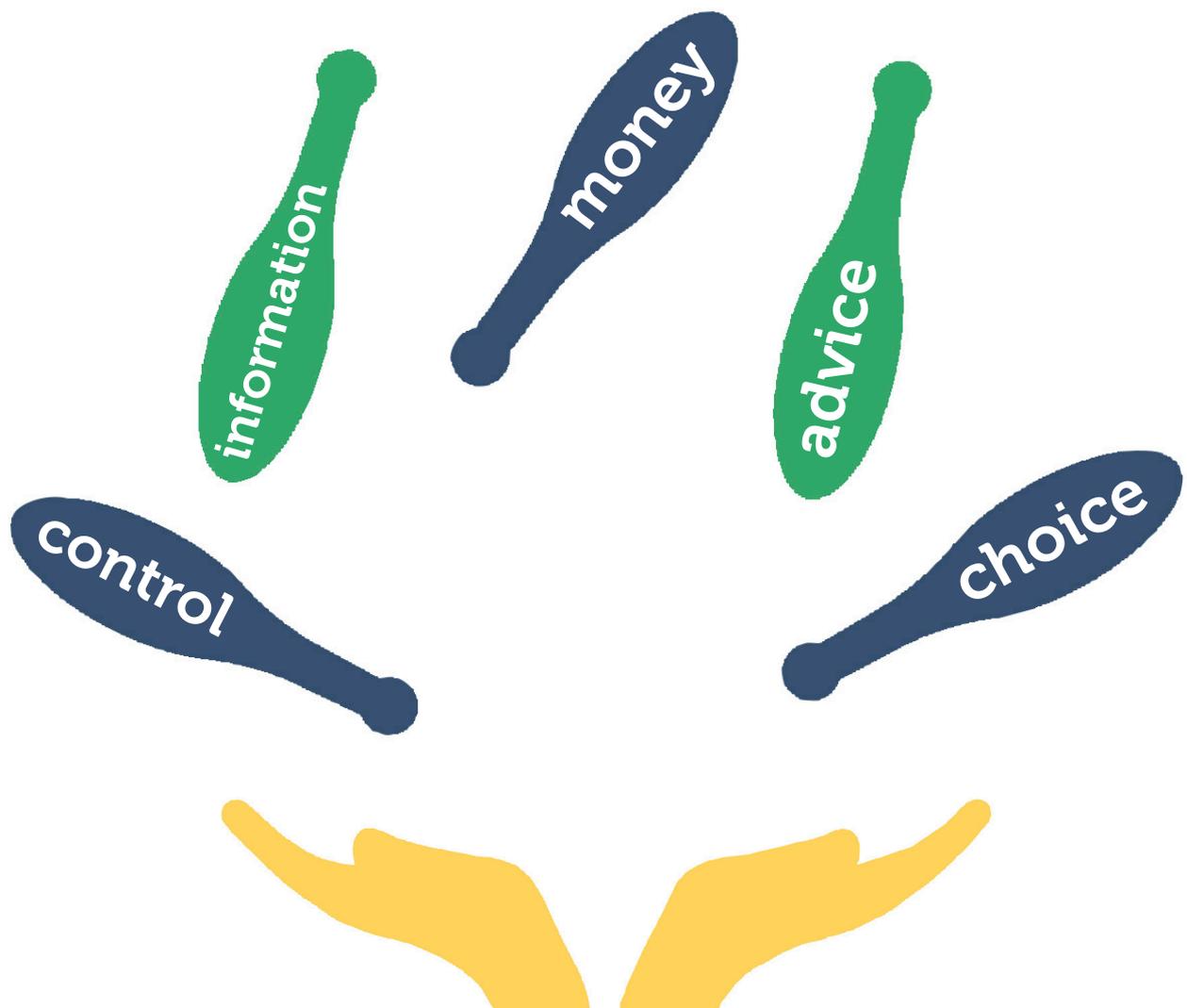


Managing the Home Care Circus

Voices of Experience: thinking ahead about care at home

A report by the Elders Council of Newcastle

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Contents

Introduction	3
Background Information	5
Overview of the Investigation	7
The Swirling Myths and Realities of Social Care	9
Reliable Sources of Information and Advice for Home Care	13
Advice and Suggestions from the Voices of Experience	15
Our Findings	18
Summarising the Messages about Home Care	26
Conclusions	29
Selected Bibliography	32
Acknowledgements	33



1. Introduction

This report describes an investigation about home care and what advice older people would give to others. It was carried out by and written for older people in Newcastle and beyond.

The findings of a small-scale mixed-methods investigative study are presented by the Elders Council of Newcastle (EC). It gives an insight into the realities of securing good home care services that enable older adults to remain at home, but with some choice and independence. All our conclusions have been gained from those with lived experience of planning and receiving home care. This work involved many older people in all its aspects including design, investigation and analysis of findings. The EC hopes to reach a number of different audiences with this report:

EC members and older people in general to raise awareness and better inform them how to prepare, seek and manage home care support

Carers and home care providers to let them know more about the users' points of view

Local authorities to provide an additional insight into older people's experiences and views of home care and support the delivery of quality home care services

Policy influencers to encourage a fairer and more person-centred system of home care

Voluntary and community organisations to contribute to their understanding of the experiences of older people receiving home care services

This report has been written during the Covid-19 global pandemic and inevitably this will change the way in which our findings might be received and understood. Older people have borne the brunt of the virus and those receiving social care more than any other group. It could be argued that the virus has amplified an ageist approach to older people (British Society of Gerontology, 2020) and increased the stereotype of them being frail, vulnerable and in need of protection (Centre for Ageing Better, 2020). At the same time the long-standing problems in social care policy, services and delivery have been exacerbated and exposed more than ever in terms of quality of life, quality of support and unmet need. However, despite the huge impact the health pandemic has had on all our lives, the EC maintains that the key messages contained in this report are increasingly relevant, at a time when voices of experience are more likely to be marginalised.

2. Background Information

Who we are

The Elders Council of Newcastle is a membership organisation run by older people who are volunteers. It is a charitable organisation that has been promoting the interests of older people since 2001. It is currently funded through support from Newcastle City Council (NCC), donations, grants and research-related activities.

At the EC we all want to make an active contribution to making Newcastle a great place in which to grow old while recognising that some of us may need help to remain independent in later years. The EC is therefore keen to ensure that older people are engaged in policy and service development and in promoting age-friendly services locally. Our range of activities includes social care, which has been one of the main concerns of our members since our foundation.

However, social care, and therefore home care, has always been a problematic subject for older people to actively get involved in and influence. This is due to the complex nature of accessing support, delivery of services, restricted help with public funding and the very personal nature and accompanying stigma of home care. Nevertheless, over the years we have received feedback from members about their experiences of services. In 2015 we accepted an invitation from NCC to explore what older people would like to see in future home care services. Our knowledge was used to good effect again in 2016/17, when the EC acted as a moderation panel to assist NCC in the process of awarding new contracts with home care providers. The EC also supported Independent Age in its 2019 campaign to get the government to introduce free personal care.

Why the EC is looking at home care now

In 2018 we conducted an informal investigation into alternative models of home care resulting in our report "Getting By With a Little Help". More recently we met with NCC senior managers and a key councillor to discuss raising awareness of the social care system and the need for older people to plan ahead. EC members then decided at our last

Annual General Meeting to make social care a top priority in the EC's work over the forthcoming year.

Despite the social care system being widely acknowledged as imperfect, the EC felt it timely to carry out a more in-depth study that would enable the authentic voices of older people to be heard.

What did we do?

In the wider context the national and local policy directives are continually emphasising that maintaining independence by older people is good for their physical and mental health. This is especially important at a time when the social care system is under severe strain. Accessing timely support also prevents the need for more costly services. Over the last decade or so there have been numerous reports about the challenges in providing quality home care services, notably by successive government inquiries, the King's Fund, the Local Government Association, and by the Which? consumer association.

What we have tried to do is something different that would not duplicate all the other sources of news and information that are already available.

A small task group of members, all with either personal or professional experience of home care, was set up to identify the distinctive contribution that older people can make in achieving a better understanding of home care. Our aim is to educate and disseminate information to our members and older people generally about support for personal care at home. With this overall aim in mind, we want to share useful sources of information about home care, dispel some of the myths about social care and raise awareness about what might help older people plan ahead for home care, should they need it.

We hope to make an impact, however small, on older people's understanding about this complicated subject and increase confidence about ways to ensure that we all have a good quality of life, with support when needed. In addition, we want to have an impact upon the thinking of others who contribute to the home care system.

3. Overview of the investigation

Managing the Home Care Circus: be the ringmaster if you can

*It's like being on trapeze reaching a service
but I'm not an acrobat and I can't jump through hoops.
I'll ride bareback if I have to
but I don't trust the lions, not even the lion tamer.
They treat me like a clown, expect me to fall over
but I'm going to conduct the band now
and be the ringmaster of my own care services.*

Vera Bolter, a former EC member, wrote the above poem almost 20 years ago. Its sentiments are just as important now as they were then. It seems nothing much has changed in attitudes towards older people and getting hold of services that keep you in control. As adults, older or otherwise, we want to maintain control and independence; one way of doing that is to be informed and plan ahead if we can.

Although this is not a formal piece of research, the EC wanted to ensure that our study was carried out as carefully and methodically as possible. We knew from previous work and our own experiences that people have different understandings of what is meant by "social care" and "home care". They often do not wish to think too hard about something that they hope they will never need. As a recent Which? report eloquently put it, older people "resist thinking about care until they need it". Unfortunately, this is often at a time of crisis (Which?, 2018). Throughout this exploration, the EC aimed to avoid a fatalistic storyline about the need for home care and instead to provide positive and valuable messages.

What do we mean by home care?

Home care does not mean the same thing to everyone. Although it is a commonly used term for paid or professional help with managing everyday tasks in your own home, other terms are also used such

as domiciliary help, health care, supportive care and home help. The language itself is contentious. We would agree with the argument by others (e.g. Social Care Future, 2020) that the dominant narrative for “care” is inappropriate and patronising: people are characterised as “vulnerable” and “in need” rather than individuals capable of living a good and high-quality life with support.

Our definition

For clarity and shared understanding, we agreed to use a working definition of home care as follows:

anything that involves professional personal care and support at home when an older person cannot manage independently, either in the short or long term.

This allowed us to include targeted services such as “reablement”, which is commonly seen as a short-term intensive support service to help someone retain or regain their ability to live independently or indeed manage again after a short period of illness. We use the term “social care” to refer to adults only and cover a wide range of activities that support people to live independently and improve their well-being. It also refers to the system that provides both public and private services at national and local level. The reality is that most older people do not receive publicly funded care. Only 21% receiving social care are estimated to receive the majority of their help from their local authority (Age UK, 2019).

What did our study look at?

With our definition in mind, we decided that our project should have three distinct aspects:

1. To explore some of the **myths and realities** about social care in general from EC members and supporters
2. To review and then **identify good-quality sources of information and advice** about home care to share with older people
3. To investigate **what advice about home care older people would give to others**, based on their direct experience of home care services

4. The Swirling Myths and Realities of Social Care

Our first aim was to:

explore some of the myths and realities about social care in general

It is a complicated and emotional subject but it's clear we need a much better social care system for older people and one that is easier to understand. As a contribution to that goal, we thought we'd try to shine some light through the fog revealing what people actually think is going on. This would provide us with the wider context of common beliefs about getting help at home and evaluate information sources to see how useful they might be.

How did we do this?

We conducted a survey among 25 EC members on beliefs about social care in general. Six statements were developed using our findings from previous work by the EC and from commonly expressed views about the social care system. We then asked older people from different groups within the EC whether they thought these statements were true or false and if they had any additional comments to make. It was assumed that participants would be better informed than most members of the public so it was no surprise that the majority knew that care is not free. A frequent comment was that it:

“Depends on personal financial circumstances and whether family support is available.”

Most respondents were also aware that choice was limited:

“ You’ll get what’s available locally according to your needs and finance. ”

On the other hand, despite residential care homes being in decline for many years, most people thought that they would end up in a care home if they couldn’t manage. They therefore agreed that:

“ This is a widely held belief. ”

However, our analysis showed that there is not a clear understanding of social care. We describe this as a “swirl of myths and realities” as opinions were so varied and underpinned with apprehension:

“ Everyone is worried how they will pay; I struggle now. ”

Any interpretation has to be treated with extreme caution as responses depended on personal circumstances and understanding of the statements. However, these tentative findings do demonstrate that, even among a better-informed audience, there are gaps and confusion about the social care system. A broad analysis shown in the chart on the next page gives some thought-provoking results:

The Swirl of Home Care Myths and Realities



What can we conclude?

- Not many think home care is free but many are very worried about costs and affordability
- A lot of respondents believe eventual residential care is inevitable but worries about quality remain
- **The swirls** reveal confusion and the need for clear understandable information
- It was surprising that around half the respondents thought they could manage home care on their own and with family. This may reflect some wishful thinking

These findings suggest that effective sources of information are needed to help people know and then access what is available.

5. Reliable Sources of Information and Advice on Home Care

Our second aim was to:

review and then identify good quality sources of information and advice about home care to share with older people

Sources of advice have changed over the years with services less accessible in local offices such as libraries, advice centres and social services offices. Paper leaflets or guides are much less common. Newcastle City Council's understandable pride in being named as 2019's "Smart City of the Year" did, however, result in some face-to-face sources of help being less available. Inevitably these changes impact negatively on older people, many of whom lack access to the internet. Although we welcome the telephone service provided by Newcastle's Community Health & Social Care Direct this may not always be seen as a first port of call. Therefore, given the complexity and changes in home care both as a system and a service, it has to be recognised that the most up-to-date and independent sources are now online. The question is to find out which ones might be most useful.

How did we do this?

We identified as many online sources of information and advice about home care as we could. The task group evaluated them in terms of accessibility, clarity, accuracy of information and relevance. All had advantages and disadvantages but finally and after several review meetings, two good "starting point" sources were identified. Therefore our recommended information sources are: InformationNOW and Independent Age.

InformationNOW

www.informationnow.org.uk

- InformationNOW is a local website for adults, their carers and families living in Newcastle upon Tyne. It is supported by Newcastle City Council, Newcastle Gateshead NHS Clinical Commissioning Groups and the Elders Council.
- It is especially valuable as it provides information about what is available locally.

Independent Age

www.independentage.org

- Independent Age is a national charity that provides free impartial advice and information on its website.
- There is a telephone helpline on 0800 319 6789
- Paper copies of leaflets and guides are available on both social and home care.

We know that many people get their information from other sources, whether it be family, friends, local community centres, a variety of websites or even social media. An obvious source is the local authority given that any publicly funded home care has to go through a formal assessment by the council. What distinguished InformationNOW is the quality of local information. It is reasonably user-friendly and kept up to date. It also provides direct links to Newcastle City Council services. We found that Independent Age is the only national website to provide leaflets and guides in paper copies as well as someone to talk to for advice via its helpline.

6. Advice and Suggestions from the Voices of Experience

Our third aim was to:

investigate what advice about home care older people would give to others, based on their direct experience of home care services

This was an ambitious aim but an important part of the project as we wanted to use the expertise and experience of EC members to contribute something distinctive and practical to the whole debate about home care locally. Raising awareness might be useful but convincing people to plan ahead would heavily rely on members sharing their thoughts about their direct experience of home care, including its planning.

How did we do this?

We developed a short semi-structured interview format with four key questions that would allow older people to share as much or as little information as they felt comfortable about. The questions were:

1. What do you know that you wish you had known before you started seeking support in the home or getting services?
2. What advice or key messages would you give to someone who might suddenly find themselves needing personal care?
3. With hindsight, is there anything you think you could have done to plan ahead for this?
4. Is there anything else you would want to say to EC members who might find themselves in your position?

These questions were framed to see the older person as the expert from whom one could seek advice rather than simply asking them for a “user perspective” when describing their experiences.

Who did we listen to?

Through the EC membership, we approached possible interviewees with the stated purpose of seeking advice, which did not require anyone to share personal information, any health issues or their reasons for needing services. Our criteria were simple: interviewees needed to have current or recent experience of home care, including reablement, and be willing to think about what advice they would give others who might find themselves in their position.

However, the task group were acutely aware of the sensitive nature of the subject so word of mouth and personal contacts were usually employed to avoid approaching anyone who might find it difficult to discuss their home care. Inevitably some people were unable or not willing to share their thoughts because of significant physical or health issues.

In January 2020 we began approaching EC members who were happy to be interviewed. Other older people were identified through local networks and supporters. Unfortunately, our interviews were then cut short by the start of the Covid-19 pandemic with the national lockdown in March 2020 and the requirement for many older people to shield. In the end we had interviewed 23 people, who included:

15 people receiving some form of home care services on a regular basis

4 people who had recently received short-term reablement services on hospital discharge

4 older carers who were closely involved in managing services for their relative

Based on a promise of anonymity and confidentiality, most people were interviewed face to face. As lockdown drew near in March 2020, a few interviews were carried out by telephone or by email. All interviews were transcribed in writing, anonymised and kept confidential. Only one member of the task group had access to all the transcripts. Of the 23 interviewees, the majority were older women. A typical interview involved someone in their eighties who lived independently but had significant mobility problems together with some sensory impairment. Of the four carers, all were closely involved in the home care and support for their mother who lived locally. Two or three interviewees had memory problems which limited the range and depth of their responses.

Analysing the results

The 23 transcripts were scrutinised using a standard approach for analysing qualitative data. Every statement was collated and examined to identify similarities and differences then analysed to develop broader categories and themes. Responses were understandably varied in the amount of detail provided. Someone with dementia found it more difficult to respond fully while others appeared reluctant to reflect on what "might have been" and what was a difficult and tiring business. Others were only too happy to pass on the benefits of their experiences and had a range of detailed and thoughtful messages to share. Indeed, some respondents preferred to discuss the questions and then respond in writing when they had had more time to think the matter through.

What eventually emerged were some very rich and powerful statements that spoke eloquently about the reality and challenges of accessing, managing and holding on to services that were constantly changing and had to be fought for. It was obvious that there was a significant financial cost involved for many people and one that also carried an emotional and often physical toll.

7. Our Findings

Six themes emerged clearly and decisively. These are listed below in order of priority:

1. Be Proactive

The need to be proactive *and* persistent was one of the clearest messages from the people we spoke to. This expressed itself in different ways from a simple message telling someone to ask for help to a feeling that you had to be firm and be prepared to follow up. The emphasis on having a certain “attitude” was very prominent and came with advice not to be ashamed or embarrassed. The following quotes indicate how much energy this might require:

“You need to push for help otherwise you might not get it. Very often agencies (do) not follow through or get in touch.”

“Arm yourself with what type of care might be required – personal, social or indeed medical. Ask appropriate questions.”

2. Plan Ahead

The importance of forward planning was also mentioned by most people. Time and time again, interviewees said they wished they had thought beforehand about the need for possible future care. It was acknowledged that this was not easy, as someone admitted:

“ I just didn't think about it, it happened and I needed help. ”

Someone else admitted that they had been:

“ told by my family that I should do something a couple of years ago.... but I didn't think things would develop so quickly. ”

One of the four carers in our interviews also acknowledged that:

“ With hindsight we wish we could have found a housing unit earlier. We should have started the process earlier...started looking earlier on. ”

Not everyone had ignored possible future needs, particularly if they had a planned operation in hospital coming up:

“ I had fully researched what was available and what I required...(so I was) fully armed when entering hospital. Ask to speak to the person responsible for making discharge arrangements. ”

Another person admitted that even though she was now getting home care, she found it...

“ ...a new experience... I had no idea what to expect...you still need to do a lot of forward planning. ”

3. Seek Advice

The majority of people who we spoke to also stressed the need to seek advice and information, as well as the importance of support along the way. Various ways of doing this were suggested, from getting involved in local NHS groups or the Elders Council itself to talking to your doctor. Some people advised that you should chat to people you already know:

“ Talk to people you know who receive care at home, if possible, from different providers. Ask around informally for the best care agency. ”

On the other hand, another interviewee advised caution:

“ Don't listen to people telling you this or that happened to them or it cost this or that amount...everyone is different so ask only for your circumstances. Don't listen to gossip. ”

However, it was acknowledged that this was not so easy:

“ It's hard getting advice, you don't know who to ask, you need good friends. I was lucky to have someone to help me through this. ”

Perhaps a direct route is a good starting point:

“ Ring the Civic Centre and ask if you need support. Ask for information as soon as there is a problem, even if you don't need it straight away. ”

4. Get Assessed and Know How the System Works

Most of the people we interviewed advised that it was useful to go to a professional to seek help and know your way around the health and social care system. Everyone who mentioned “the system” felt it was very complicated and that the different parts did not always work together well:

“The services are not joined up – you end up confused about who is offering what and how they all fit together.”

“When you are involved in the system you are just grateful for support – however I still have no idea who I would contact to increase support.”

It was felt that the complexity of the system was compounded by the changing nature of services and provision:

“Things change all the time. Services come and go. Services have been reduced.”

However complex the organisational arrangements between social care and health might be, respondents advised you had to go through the formal process to find out if you could get support from the local authority. This meant being subject to a formal assessment by the local authority to find out what your needs might be. It was known that difficult and complex processes of getting assessed might not even achieve anything. It was only if you met the strict eligibility criteria that you might get help. As one older carer told us:

“ The level of pressure on local authority resources is high and they ration help by being very slow to assess anyone. They need to be pushed to get an assessment done, for example, getting letters from doctors, consultant and other professionals. ”

Almost everyone spoke about this process of getting services, knowing what services were “out there” or the costs involved. However, there were several concrete suggestions about how to improve your chances such as:

- making a checklist of what things to ask
- enquiring about alternatives
- being as specific as possible about what help you require
- not expecting too much from an initial assessment from Adult Social Care
- approaching the GP for a social prescription

At the same time, it was acknowledged that:

“ Independent people might find it hard to accept others doing things for them. ”

5. Find out about Specific Services and the Costs Involved

There were numerous mentions of specialist services alongside advice about finding out as much as you could about these services. One piece of advice was to draw up a list of such services to have at hand.

Apart from home care in general (e.g. having someone come to the house daily to help you with everyday tasks) other services that older people found useful included:

- community rehabilitation and support teams (short term)
- laundry services
- aids and adaptations around the house
- incontinence support
- advice and services specifically for people with sensory impairments
- having help with meals at home
- a visit by an occupational therapist before a hospital stay
- alarm equipment and a 24-hour response service
- checks to ensure that you took your medication at the right time

Most of these suggestions were accompanied by words of caution to manage expectations such as:

“ Don’t expect good timekeeping, be prepared to explain, communications are not always good. ”

“ They come in and out and don’t stay long; it’s very variable. ”

“ Try and get the right person. Try to avoid having too many carers, different ones too often. ”

Warnings about the financial costs involved were also made as getting care and support was known to be an expensive business even if you did get some financial support from the council. The key messages from those with experience in this area were stark. Expenditure could be very high so you either needed a good income or savings otherwise costs could be prohibitive.

“Be aware that private care may be absolutely necessary and you may be left to seek this out yourself. Expect to pay between £15-25 per hour for home care.”

Even so, we found that some people did not expect this, as indicated by the comment below:

“I always thought the services were free. I thought that as we'd paid taxes, that this would all be sorted for us in later life.”

It was recognised that reablement services were free for the first six weeks, but otherwise a key message was to make sure you claim for any financial help available. This could be attendance allowances, pension credit or other benefits (if eligible) or even a blue parking badge. There is also support for home adaptations, such as the Disabled Facilities Grant.

6. Sort Out Legal and Financial Matters

As well as the costs involved, many of our respondents advised that it was really important to sort out any legal and financial matters if you were in a position to do so. This is a particular aspect of planning ahead but one that some people had strong views about. Apart from

the obvious messages about making a will so that things are taken care of when you die, several people mentioned getting a Power of Attorney document set up in case you found it difficult to manage later and decisions might need to be made about your health and other matters. One person told us that “everyone should be encouraged to make one” while someone else recognised that you should:

“ *...be prepared for difficult conversations for example about resuscitation.* ”

One of the predominant worries of older people was how to pay for adequate home care when it is needed. Among those who gave advice about legal and financial matters, it was felt that it provided peace of mind, even if your family might see things differently:

“ *Well I’ve made a will so everything will be taken care of when I die. I haven’t done anything yet about making sure I will be looked after if I can’t make a decision myself. I will rely on my sister to do that but she keeps telling me to put something in writing soon.* ”

8. Summarising the Messages about Home Care

The information and advice given by older people with direct experience of home care are powerful and heartfelt. They provide an insight into the reality of the challenges involved in trying to live independently and maintain some control when support is needed simply to live an ordinary life. The messages we heard should enable us all to be better informed on how to do this for ourselves or for a loved one. One way to think about all the themes above is to envisage these in three key stages.

Stage 1: Planning and looking to the future

Predicting the future is an impossible task but a striking theme from our findings was how important it was to be proactive and plan ahead. This creates significant challenges as the reality is that most of us will not want to think about care until we need it. Being older can be hugely positive, but the experience of many of us is that an ageing body may bring unanticipated challenges. As one EC member explained:

“I thought getting older was going to be a sumptuously rich experience but this is not the case. My smooth transition into older age has been crunchier than I planned.”

The EC manifesto makes it plain that we want to use our experience and skills to encourage older people to think ahead and be well informed. Just knowing reliable sources of information and advice such as *InformationNOW* and *Independent Age* become useful in keeping abreast of what help might be around.

The key messages from those we spoke with underline how important

planning is, even though it is underpinned by a sense of anxiety. In many cases a focus on practical ways to prepare might mitigate this apprehension alongside support from family or friends. Useful methods to plan ahead varied from having difficult discussions with family and friends, putting any legal and financial matters in order, being aware of how the health and social care system might operate or even having some idea of who to ask if a need arose. Looking ahead was part of a continuous journey that involved keeping up interests and activities but with an eye to the future. These are all messages that the EC will continue to promote as part of its remit to inform and put people in the picture.

Stage 2: Getting support

The health and social care system is not currently designed to help people get support or make well-informed decisions quickly. “Ask for help” was the expression most often used in our investigation despite people knowing that this was a big step and difficult to actually do. The immense challenges in meeting strict eligibility criteria in fact often meant help from public services was not forthcoming. Time and again older people or their carers told us that you needed to be proactive, persistent and push for help. Finding allies and keeping up good relationships with families and friends was useful in ensuring that you were not alone in this. Trustworthy information sources have already been suggested, but getting support also relied on seeking advice from someone knowledgeable about the issues.

Inevitably it is easier to respond to people you trust so another key message was to find someone in whom you had confidence. This could be professionals such as a GP, a request for a formal assessment from the Local Authority or simply someone who was already receiving home care. For the EC, the importance of building and maintaining a support network to rely on was the key to getting services and navigating a system that can be frustrating and unreliable. It is knowledge and good relationships that underpin any effective and useful support.

Stage 3: Choice and control when using services

Another theme emerging from our study concerned the reality and complexity of using services once you had got them. There were poignant efforts to have some choice and keep some control. The financial costs of receiving care were often seen as a crucial part of managing the system for a good quality of life. Many respondents had a huge wealth of knowledge about the variety and specialist nature of services and were very clear about what you must and must not do. Those people with long experience of using home care, particularly with other forms of care, recommended keeping a list of everyone who came in and out of your home or keeping a diary of what was going on. To use a metaphor from the circus, there was a real need to be aware of “keeping your balance” and “being a juggler trying to please” while trying to keep up to date about services and manage a system that was often outside one’s control. This is where listening and learning from the voices of those with experience becomes so central to being happy with home care.

There has to be a caveat to this message, however. None of the people we interviewed who received publicly funded services were using any alternatives for getting these such as direct payments or personal budgets. Such approaches are often identified as ways of increasing control when seeking support. This has certainly been the experience of at least one EC member. However, according to a national independent charity, the evidence is unclear whether these make a great deal of difference, particularly among older people (King’s Fund, 2019).

9. Conclusions

The Circus Concept

We have called this report *Managing the Home Care Circus* because the imagery of the circus and its associated risks and perils appear only too relevant to the home care experiences of our members and supporters. Metaphors such as “jumping through hoops”, trying to “conduct the band”, “being a juggler trying to please” and “walking a tight rope” can all be readily applied to those individuals who found themselves wanting to maintain some independence and dignity.

However, there is a wider implication in the sense that home care support involved various acts by different performers at different times and often the user did not feel in control. The importance of “being the ringmaster” (i.e. being in control) was an aspiration advocated by many of those to whom we spoke. What emerged from our investigation was the overall importance of people wanting to be in control when trying to maintain a certain quality of life *despite* the need for extra support and help at home.

Our original aim was a form of peer support: to educate and inform ourselves and other older people about home care. We need to raise awareness and build confidence when pointing people in the right direction at a time that may be acceptable for them. To sum up, we want to be positive but realistic about our future even if we need a little help to do this. We want older people to take on the following findings from our project.

Our key messages

1. **Be proactive in asking for help**
2. **Plan ahead: get thinking about the future**
3. **Seek advice and get support**
4. **Get assessed and know how the system works**
5. **Find out about specific services and the costs involved**
6. **Sort out legal and financial matters**

Below is how we plan to do this.

Getting these messages out there

We will share our key messages in the following ways:

- Present this report to as wide an audience as possible. This includes distributing the report to those who made it possible and older people in general, circulating it to those who can influence policy and services and making it available on the EC website. Where appropriate, paper copies may be provided.
- Create a digital animation video with Digital Voice of the key messages from older people themselves. Six characters will speak about their experiences and give advice. The words used are directly from our anonymised transcripts.
- Write regular features on different aspects of home care in The Echo, the EC quarterly magazine.
- Produce a feature on home care on Older Voices, the EC's regular radio programme, and other networks.
- Publicise the report on the fortnightly EC online bulletin, the EC Facebook page, Twitter and other forms of social media.
- Give presentations, virtual if appropriate, at other events and to sister organisations.
- Share our messages with other organisations such as Social Care Future, the Later Life Audio and Radio Co-operative (LLARC) and InformationNOW.
- Link the findings of this report to the EC work on 'Doorbells – dreaming for the future'. This theatre performance encourages people to think about their housing and care needs.

Where next?

By undertaking this study, the Elders Council hopes that we have offered older people insights into how to make the most of the current care system. However, this does not mean that we believe that the system as it currently operates, with the demands it places on older people and their families at a time when they need support, is fit for purpose. Successive governments have been well aware that the social care system is in need of much reform if it is to meet the needs of an ageing population. Reports have been written and shelved while care has been a crucial element in general elections. However, successive governments seem unwilling to grasp the nettle of reform or fund the system so that it can fulfil its proper purpose.

The Elders Council is adding its voice to those bringing forward new ideas for a more effective care system, so that we don't have to spend our later years as "ringmasters of a circus", but can be confident in receiving support that enables us to enjoy a good quality of life. We support the vision laid out by Social Care Future:

“ We all want to live in the place we call home with the people and things we love, in communities where we look out for one another, doing things that matter to us. ”

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