

# Reshaping Care for Older People



## Draft Joint Commissioning Carers Consultation sessions

### 1 Background

In Glasgow, the NHS, social work services, the Third Sector and the independent sector have produced their Draft Joint Commissioning Plan for 2013-2016. The plan sets out a vision for the development of services over the next three years. A city-wide consultation was launched on 15<sup>th</sup> April 2013 to engage with older people, carers and others, with an interest in the proposals, to discover their views on the plan.

Due to their collective 'reach' with Carers, GCVS worked in partnership with the Carers Coalition and the Third Sector Carers centres to carry out a series of 'voice and engagement' sessions with older carers and carers looking after older people in the city. The aims of the sessions were to introduce carers to the plan and to ask for their opinions on the key issues.

Two events were held in the city, one in the South and one in the West. The event in the South was held in Dixon halls and was delivered in partnership with Dixon Carer Centre and the South East Carer Centre. In total, 30 carers attended, all of whom had some involvement with their local carer's centres. The event in the West was held in the Pond hotel and was delivered in partnership with the West Carer centre. In total, 12 carers who were actively involved with the West and North West Carer's centres attended the events.

### 2. Introduction

In the paper below, we provide an overview on the process undertaken to consult with carers on the Draft Joint Commissioning Plan. We have also outlined the key asks that they deemed crucial in supporting them in their caring journey and their views on what it will take to shift the balance of care towards greater investment in preventative and anticipatory care, and proactive care and support at home.

### 3. Format

The session format included: a short presentation giving an overview of Re-shaping Care and Joint Commissioning, an explanation of the Care Pathways and examples of what this will mean for carers. In addition, participants were shown the Joint Commissioning DVD, which shows representatives from the four partner organisations talking to older people about the relevant issues.

In the first half of the session, participants were asked to take part in a message board exercise sharing their experience as a carer within the four care pathways, which is described in more detail below.



On the day, four message boards like the one in the image to the left were displayed around the room covering each of the care pathways namely,

- Preventative and Anticipatory Care
- Proactive Care and Support at Home
- Effective Care at Times of Transition
- Hospital and Care Homes

Each board had a number of questions relating to the key stages in people’s caring journey which were related to each of the RCOP care pathways - asking them to detail what had:

- a) *Worked well for them?*      b) *Worked quite well?*  
 c) *Not worked so well?*      c) *Made things worse?*

In the second part of the session participants split up in to smaller discussion groups to answer a number of consultation questions.



The overall aim of the discussion groups was to identify:

- a) Which services produce the best outcomes for carers and the people they care for, and should be invested in?  
 b) Which services do not achieve good outcomes and need to be re-designed, or could potentially be cut.

For more detailed information on the feedback received at the events please see **appendix 1**

### 3. Overview of feedback to the plan

Like the other groups consulted carers broadly agreed with the vision laid out in the Strategy and understood the drivers behind the changes, however, they felt that more detail on what would happen over the next 3 years was required. In addition, they felt strongly that one of the most effective ways to begin to reshape care for older people was for the partners to take time to clearly understand the needs of carers in looking after the people they care for. One of the overarching frustrations shared by carers at the events was that they often felt that their role wasn’t fully recognised and that for some, their opinions and needs were often ignored.

As a large percentage of carers are older people themselves, it was suggested that it was short-sighted of partners not to fully recognize their role and the support they need to continue in it.

## 4. Emerging Themes

From the overall feedback received, the common themes that emerged as requiring greater focus, commitment and supporting detail within the plan were as follows:

- short break , respite and good quality day care services (with associated transport for the frail and disabled )
- local information points and advice and support services
- listening to and recognizing the role of the carer
- partnership working and joined up approaches to support earlier intervention and prevention
- person-centred home care support packages that align with the principles of SDS principles
- access to aids and adaptations, specialists, suitable housing options and long waiting lists

In the following sections we provide an overview of the points raised, including examples of the current challenges faced by carers and the key asks they make in response to the consultation.

### 4.1 SHORT BREAK, RESPITE AND GOOD QUALITY DAY CARE SERVICES (WITH ASSOCIATED TRANSPORT)

#### Current Challenges

From the feedback received, it was clear that building-based day care services and respite acted as one of the biggest supports in helping carers keep the person they looked after healthy and well. There were, however, some participants who experienced difficulty in sourcing good quality day care due to long waiting lists, the absence of good quality provision and the lack of suitable transport options to access services. The latter was particularly true for people looking after someone with a disability or for those with limited mobility.

However, on the whole, the majority of participants were happy with the day care and respite they receive, but were concerned that such services in the future may no longer be available due to the continual cuts to day care type services.

#### Key Ask

When carers were asked for their three big asks, they requested that partners fully recognize the importance of short breaks and respite and the importance of continuity of care staff entering individual homes. They also asked that more detail be given on the commitment to short breaks within the plan. Additionally, they felt it was important that a clearer definition be agreed as to what constituted a short break, suggesting that anything less than 4 hours would not suffice.

As part of their feedback on short breaks and respite, carers also commonly mentioned transport as a barrier and asked that consideration be given to future investment in improved transport links and community transport, in order to ensure better transport links within and between local communities and to assist older people and their carers retain their interests and thus, their independence.

To conclude building-based services, and building based respite were most commonly cited as being a life line to carers both in enabling the carers to have some time to themselves, while also

ensuring that the person they cared for was having a quality experience, socialising with their peers in a safe environment.

**One participant said:** *“Be careful of older people’s health. Older carers need more support to protect their health – cuts to their short breaks services leave them exhausted and feeling like they can’t continue to care*

## 4.2 LOCAL INFORMATION POINTS AND ADVICE AND SUPPORT SERVICES

### Current challenges

Many carers in attendance reported having to frequently chase professionals for information and support, and also shared stories of receiving inaccurate advice, and/or inadequate support packages.

In particular when referring to information and advice carers referred a lot to the role of their GP as being crucial. They shared both positive and negative stories about the support they had received from their GP however, all in attendance recognised that GP’s had a key role in assisting carers to access services early in the caring role.

Also, some participants identified early diagnosis support as being thin on the ground and/or difficult to access, due to long waiting lists, which ultimately led to delays in the allocation of support packages.

Conversely, the one service that was mentioned as most valuable in this area was the support they received from carer’s centres, both at the beginning and throughout their caring journeys. In particular, what they valued most was being able to access information about the services and supports available, while being able to meet other carers and develop peer support networks. Many also valued being able to rely on the carer centre staff they had a relationship with when times got tough.

**One participant said:** *“Carers centres have been the best - could not fault them – they are always there for you and it helps you to meet other people too”.*

In addition, condition-specific organizations, such as Glasgow Association for Mental Health, Alzheimer Scotland and Glasgow Disability Alliance, were commonly mentioned by many carers as having helped them to navigate the support system and to obtain early diagnosis and post-diagnosis support that met their needs

**Another participant said:** *“Ensure carers have the right information at the right time – information needs to include clear details of services that are available and how to access them*

### Key Asks

The need to better resource information and advice services was raised repeatedly, particularly those that can assist carers to access accurate advice about the services and support on offer.

The areas of advice that were mentioned most commonly as being helpful included:

- Information from carers' centres and condition-specific organisations
- Early diagnosis and post-diagnosis information and advice
- Information and support from district nurses and GPs

(The three areas above ranked as most helpful to carers in their role)

- Medication management
- Information about local services and activities
- Advice about finance and power of attorney/guardianship
- Help to navigate services and support at the beginning and throughout the caring journey

#### 4.3 PARTNERSHIP WORKING AND JOINED UP APPROACHES TO SUPPORT EARLIER INTERVENTION AND PREVENTION

##### Current Challenges

A common challenge described by the carers in attendance was that they felt there was a lack of integration between partner agencies, often resulting in conflicting advice and information and unnecessary and repetitive assessment processes.

**One participant said:** "it would help to have a key manager that would follow you through the system to ensure you received the right package of support for your needs at the right times to avoid crisis"

They also identified obtaining early diagnosis support as challenging and stressful due to the cluttered partnership landscape and conflicting information and advice provided by partner agencies. However, it should also be noted that carers that had received support from condition-specific organisations, such as those previously mentioned, were very positive about the early diagnosis support they had received.

##### Key ask

Carers asked that greater investment is given to developing joint assessment processes and earlier diagnosis of health issues. They also asked that a clear commitment be given to improving partnership working and information sharing processes to:

- prevent people from having to re-tell their stories
- Reduce overlapping assessment processes and general bureaucracy
- Ensure that treatment and support package are put in place to avoid crisis situations arising.

**Another participant said:** "it really doesn't help to be reassessed continuously throughout your caring journey it just adds more stress"

#### 4.4 EQUITABLE COMMISSIONING PROCESSES THAT ALIGN WITH SELF DIRECTED SUPPORT (SDS) PRINCIPLES & HOME CARE SUPPORT PACKAGES

##### Current challenges

Many examples were shared by participants regarding their dissatisfaction with the packages of support the person they cared for was receiving or had received. The most common criticisms

included the lack of a person-centred approach and packages of support that were overly task-focused. Other aspects that were mentioned as causing stress were the lack of:

- Consistency of staff entering the home
- Time allocated in some instances
- Meaningful dialogue with older people and their carers when packages are allocated (this was cited as a major source of stress)

**One participant said:** “We need services to be flexible and coordinated based on the needs of the person and not what the provider can offer”

#### Key Asks

Carers made a strong call for the redesign of home care packages in order to:

- Offer more flexibility, to ensure that support meets the needs of older people and their carers.
- Ensure adequate time is allocated to packages of support
- Ensure consistency of staff entering an individual’s home

#### **4.5 ACCESS TO AIDS AND ADAPTATIONS, SPECIALISTS, SUITABLE HOUSING OPTIONS AND LONG WAITING LISTS**

##### Current challenges

OT’s, Podiatrists, falls assessments and specialist support services ranked highly as good sources of support in assisting carers to keep the person they cared for at home. They spoke of the importance of being able to access these services when required and at a local level, where possible.

However, many carers reported having to fight with and/or chase professionals to obtain the correct aids and adaptations and specialist support. This was cited as a major source of frustration, due to the vital role that this type of specialist support has in helping older people live independently at home.

Also, throughout the consultation, long waiting lists were cited as one of the aspects that hindered carers in getting the person they cared for the support they required to stay healthy and well. Some shared stories of how situations had escalated to crisis point, while the person they cared for was on a waiting list, which they believed could have been avoided if timely and appropriate support had been in place.

**One participant said:** “Having to fight for services – it’s exhausting”

##### Key ask

Carers asked that the plan details the level of investment and commitment that would be allocated to reducing long waiting list for aids and adaptations and access to specialist support such as OT, Podiatrist, falls assessments, etc.

Participants also believed that the provision of after-stroke care should be prioritised, with access to speech therapy, physiotherapy and dietary advice on leaving hospital, which would help to increase

a person's confidence in managing their own condition and their ability to live independently at home after a hospital stay.

#### 4.6 LISTENING TO AND RECOGNISING THE CARER'S ROLE

##### Current Challenges

Many carers shared examples of good practice where GP's and health professionals fully recognised their role as carers and ensured they had enough support in place to help them to look after the person they cared for. However, many also shared stories about not being listened to, or properly involved in the assessment process. They found this exhausting and stressful, saying that it often led to the allocation of insufficient packages of support.

**One carer said:** "What helped me was having a good G.P that identified me as a carer and made sure my mum had the care she needed – very pro-active in terms of healthcare."

##### Key ask

To ensure that professionals are aware of, and trained on, the importance of recognising the carers' role. This included listening to the carer, while also recognising that they too may require support to help them look after the person they are caring for, when packages of support are bring agreed.

**Another said:** "*Hospital discharge teams – must take account of carer's role and responsibilities.*"

#### 4.7 Equalities

Carers in attendance from BME Communities urged partners to invest in creating a greater cultural awareness when designing services and approaches to working with older people and their carers. They also felt that greater investment should be committed to the following:

- Improving provision of day services to care for older people from ethnic minorities
- Employing more ethnic minority development workers
- Greater investment in interpreter services, particularly within hospitals and especially around discharge planning processes

**One participant said:** "We are way behind, England are much more advanced in the cultural awareness issues"