

# Carers of the Over-65s

A local perspective by Healthwatch Croydon



July 2016

“I want to live an independent life for as long as possible.”

Croydon Resident, 2016

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## Foreword

Of Croydon's estimated population of 380,000, around 50,000 are aged 65 or over, and it is this group that is 'most likely to need informal care'.

According to the Carers UK annual survey of carers (State of Caring 2016), 54% of carers expect their quality of life to get worse in the next year and only 6% expect their quality of life to get better. To what extent does this reflect the local experience?

Healthwatch is the official 'patient voice' across England. Established as part of the Health and Social Care Act 2012, we champion the views and experiences of health and social care service users. As part of our work, we have listened to local people's stories about their caring experiences and aspirations.

Those caring for a person over the age of 65 tell us that discharge arrangements are not always seamless, support at home can be lacking, multiple care plans are not holistic or helpful, and assessments for allowances can be lengthy, complicated and impersonal.

Of course, this is not representative of everyone's experience and it's more often the case that things work out fine, but it doesn't mean we can ignore, or marginalise, those carers and families who confide in us, when things go wrong.

Many informal carers (particularly family members) say there is an expectation that they will find the time and resource to look after their loved ones, with minimal (if any) assistance. They do not feel recognised as carers. When public finances are tight and services stretched we can all be expected to 'do our bit', but we all have our limitations, and when help is *really needed*, it should be there.

The alternative, is that more people become unwell, physically and mentally, placing acute care in ever greater demand. The NHS must 'pick up the tab' for the additional cost and burden this creates, to the detriment of other services. We all know this is unsustainable, and we may also suppose that the problems will increase in the immediate short term.

It is therefore vitally important that we 'take heed' of what residents, and professionals, are telling us now, so we may better plan for the future.

*The Healthwatch Croydon Team*

**“ Health and care services are working in silos. ”**

**Social Worker**

## Executive Summary

Healthwatch is the official ‘patient voice’ across England. Established as part of the Health and Social Care Act 2012, we champion the views and experiences of health and social care service users.

### The Experience of Carers of the Over-65s

Healthwatch Croydon, the local consumer champion, has researched the experience of people caring for the over-65s.

Building on our report of the discharge experience of the over-65s at Croydon University Hospital, we have decided to examine in more detail the wider determinants, such as access to social care, care planning, assessments and allowances, and provision of advice and information including on the Care Act 2014. We also revisited hospital discharge.

### Key Findings

Engaging with 46 people, and with 134 items of feedback in our database, we found that:

#### *Hospital Discharge*

Communication plays a key role in the majority of complaints, whether that is providers not sharing information, patients confused at the point of discharge, or carers and family not involved in decision-making. Advice around medication also needs to be concise.

#### **We said:**

- *Although communication is everybody's responsibility, there needs to be a clear audit trail of who at the hospital is responsible for the discharge process, and when. We can then be reassured that essential information has been communicated, and also trace the causes of any problems (such as a care home not notified of a discharge).*
- *Clear instructions on all medication, such as dosage, should be provided and checked at the point of discharge.*

#### *Support at Home*

We have heard that it can be difficult to access support as and when needed, with experiences of delayed, minimal, or no support at all. Care workers do not always let families know if they are late, or not coming.

#### **We said:**

- *Social workers' telephones should be answered more often, and when not, messages need to be responded to timely.*
- *Care workers should be able and equipped to phone clients whenever necessary, especially when not able to keep to agreed times.*
- *GPs, or community health services should be able to provide assistance in cases where a clear health risk exists that the 'system' is not configured to deal with, such as cutting the nails of an arthritic lady.*

## Care Planning

Residents and carers tell us that the health, mental health and social care professions use separate care plans, which are not directly linked, leading to care that is not as holistic as it could be. This also presents a potential obstacle to integrated care.

### We said:

- *Care plans would work better if ‘pulled together’ to be useful to multiple professions. This has been achieved in other boroughs through use of a software package.*
- *Care plans should fully reflect the needs of the individual and not, as some GPs feel, be tick-box exercises.*
- *Carer input should be sought and included.*
- *Referral onto holistic pathways can be onerous for GPs so flexibility around self-referral, or multiple points of access, may increase entry into life-enhancing services.*

## Allowances and Assessments

Carers should know about their rights and entitlements, particularly under the Care Act.

### We said:

- *When engaging with people, we found that nobody was aware of the legislation, and therefore, not educated on all of their options. Accessible, easy to read information should be widely available.*

It is the role of Healthwatch to influence the commissioning and delivery of services, therefore our recommendations are not prescriptive, but intended to inspire solutions to the issues that clearly exist.

### Looking to the Future - ‘Outcomes Based Commissioning for the Over-65s’

Croydon Clinical Commissioning Group (CCG) and Croydon Council intend to commission a single ten-year contract for managing and delivering services for the over-65s who live in Croydon. Other partners include Age UK Croydon, Croydon Council Adult Social Care, Croydon GP Collaborative, Croydon Health Services NHS Trust and South London and Maudsley NHS Foundation Trust.

The aim is to encourage 65-75 year old people, and their carers, to recognise the benefits of having ‘information and relationships which complement preventative health and care services’. By integrating health and social care services, we may be better able to ‘wrap services around people, based on their individual need’.

This presents a real opportunity for carers, who can potentially benefit from the more personalised support that the cared-for will receive.

## 1. About Carers

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

## 2. Carers in Croydon

Carers enable the people they care for to remain at home rather than move into residential care. This way, they are more likely to live full, safe, healthy and even longer lives, affording them their dignity and independence. Of Croydon's estimated population of 380,000, around 50,000 are aged 65 or over (Office for National Statistics), and it is this group that is most likely to need informal care.

Some carers cope very well with their caring responsibilities and are determined to provide support to their loved ones themselves. But others need help because their caring responsibilities are very onerous, impacting on many aspects of their lives, or because they too are vulnerable, frail, sick or disabled. It is in the interests of those carers, of the people they look after, and of the state, that we provide carers with timely help and support, and sometimes just recognition, to help them to carry on caring.

### 2.1 Carers' Rights

Various pieces of legislation, particularly the Care Act 2014 give carers specific rights - the right to an assessment, the right to a direct payment if entitled to assistance, and employment rights such as flexible working.

### 2.2 Access to Services

The vast majority of carers do not come into contact with Croydon Council because they are either not aware of services available or do not want or need support from the council. A proportion of carers do come into contact with the council when they or the person cared for applies for help with social care and support whilst others will contact carers organisations.

The most common types of service used are advice and information, and breaks (including activities). Quite small proportions use training, education and employment support, emotional support and befriending - possibly, a consequence of not knowing where services are to fully support them.

## 3. The Impact of Caring

Carers may themselves be ill, frail or disabled, and they themselves could fall within the protected groups under the Equality Act 2010.

**“ I wish people would treat me as an individual. ”**

**Elderly Resident**



The Croydon Carers Strategy 2011-2016 found that a quarter (26%) have a long-term illness, 24% a sight or hearing loss, 21% a physical disability, and 11% a learning disability or mental health problem (some had more than one of these characteristics). In other words, the carers are not so very different from the people receiving the care. In some cases family members are looking after each other, for example a daughter with a learning disability and her elderly mother.

Almost one in 10 carers (9%) said they were in bad or very bad health. Indeed, the caring role can cause or exacerbate health problems. The national general household survey in 2009/10 found that half (52%) reported that their health had been affected, 42% said their personal relationships, social life or leisure time had been affected and 26% their ability to take up or stay in employment. Not surprisingly, 72% of those providing 20 or more hours of care a week reported poor quality of life. There is a significant correlation between carer burden and increased use of mental health services.

Many studies attest to the wide-ranging benefits for carers of interventions. There is no universally effective intervention, and interventions need to be tailored to different condition groups, carer communities and stages of caring. Moreover, the preventative role of good informal care is well-documented. People without a carer are more likely to be admitted to nursing or residential care: carer stress accounts for 38% of admissions, and family breakdown (including loss of a carer) for 8%.

Informal carers - people who look after their relatives, friends and neighbours when they are vulnerable through old age, disability or long-term conditions and illnesses - are important, and equal partners, in our society. They save the state money by providing the care which would otherwise be the responsibility of local authorities or the health service. A report in 2011 by Carers UK and the University of Leeds calculates the value of care provided by carers in the UK to be a staggering £119bn per annum.

#### 4. The Local Experience

As the borough's 'official patient voice', Healthwatch Croydon has listened attentively to local people's experiences of caring for the over-65s.

Our main offices are located at the Carers Support Centre and this enables us to engage regularly with professionals who tell us about leading trends, and with carers, who drop-in throughout the week to attend various activities, support sessions, and to simply talk about their experiences.

As part of Carers Week 2016 (6-12 June) we held a Carers Listening Event on 6 June, hosted an Information and Signposting Stall at the Carers Information Day on 8 June, and conducted a carers edition of our Patient Experience Panel on 10 June.

We have also met with carers around the borough, visiting the Blue Orange Café on 7 April 2016, amongst other venues. Engaging with 46 people in total, and with a total of 134 items of feedback in our database, we have evaluated their collective experience.

**“ I have 3 different health and social care plans. ”**

**Elderly Resident**

#### 4.1 A Snapshot of the 'System as a Whole'

A resident talks about her recent experience of caring for her elderly mother. We have used this as a case-study as it illustrates a broad range of services, including:

Urgent Care (Ambulance and NHS 111), Telecare (Care Watch), Hospital Inpatients (Acute and General), General Practice (GP and Out-of-Hours), Occupational Therapy, Hospital Transport, District Nursing, Social Care (Domiciliary Care), Community Pharmacy, Residential Care Home, Community Organisation (Advocacy and Advice).

Although not representative, it is interesting that in this case some elements work well, some do not, while others are variable:

"Mum is 92, she was living on her own and in reasonably good health for her age. She fell down the stairs and knocked her head - she was taken to Croydon University Hospital where she had full scans and tests, and a six week care package put in place. They referred us to the Carers Support Centre, and helped to get a Care Watch alarm fitted.

Mum was never the same after the fall, her ability to concentrate had deteriorated. The GP increased her medication and was concerned about her health.

I'm not that impressed with Occupational Therapist, who arrived in a taxi to deliver mobility aids. She was curt and said 'I can't be here long, I have just half an hour'. Not very impressive.

Later in the week Mum collapsed in the hallway at 11.00pm - we were alerted by the neighbour who made sure the Care Watch button was pressed. It was deemed an ambulance was appropriate, which took over two hours to arrive. Mum was confused, her legs had collapsed underneath her. We rang London Ambulance Service three times in that two hours as Mum was crying in pain - she was eventually taken to Princess Royal Hospital.

Mum was kept in overnight and discharged at 11.30am - she eventually got home at 6.00pm, throughout which time she had no food. There was confusion about securing a wheelchair and the one driver who turned up wasn't enough for the task (Mum lives on a top floor maisonette and it takes two people to lift her). What would've happened if I hadn't mentioned it?

We spent a couple of days with Mum, she was okay and then we went home. The next day she was in pain in bed - the neighbour called Care Watch and we got there promptly as it was a suspected heart attack.

This time, because of the nature of the incident, the ambulance crew arrived quickly and were very good. Mum was taken to Croydon University Hospital and the clinical staff were excellent. I'm not so sure about the nursing care, as I had to prompt the nurses (on more than one occasion) to lift Mum out of bed and into the side chair. I think too much time in bed had affected Mum's mobility as she couldn't stand up by the end of the week. Physiotherapists don't work at the weekends and I raised concerns with staff.

I know the prime concern of the staff is to keep patients well, but keeping people 'ticking over' is all they seemed interested in - what about the quality of life while on the ward, I think stimulation is extremely important. Mum was so bored she said she would be happy to go to a Care Home - something she was against before.

One day I couldn't see Mum on the ward - she had been discharged. I was not informed even though I am the next-of-kin on all documentation. I asked the nurse where Mum was and she said 'she's gone - I'm surprised to see you here'. They said they'd phoned me, but that's not the case. Apparently Mum had been told the day before. They had called my brother and not me.

Mum had left the ward after lunch and arrived at the Care Home at 4pm. Hayes Court - I can't fault them. She arrived with medication but no notes on dosage (we had a very limited timeframe to clarify, due to the nature of the medication). On speaking with the hospital it was found that her records contained incorrect information - but were correct on admission, so something went wrong somewhere. The Home said they often receive patients from the hospital with no (or incorrect) medication, and no notes.

We got a stair-lift installed. The occupational therapist said her home was now suitable to move back in, however the care home was concerned about Mum's depression and anxiety. A care package was arranged which seemed good - a physiotherapist comes in the morning, a district nurse during the day to prepare the main meal, and somebody in the evening to wash, give supper, medication and put Mum to bed. One day the evening assistant hadn't turned up - Mum gave up waiting and put herself to bed. She eventually did arrive, but at 11pm and Mum was terribly scared. They did not give medication.

I got a call from Mum the next day - nobody had come again - she was stuck in bed without food or medication. The manager said Mum was due a visit at 9.00am and it was 'an oversight'. They tend to give fresh food in the morning and leave a plate of covered/wrapped food for the evening (this I didn't know). Later in the week the house key wasn't put back properly in the safe - the council were very good and sorted it the same day. Nobody came to give lunch but they phoned to apologise.

At one point Mum was feeling unwell - she had diarrhoea so we went to the pharmacy. The district nurse phoned NHS 111 as Mum was still unwell the next day. They said they would get a doctor out within six hours - they actually came after thirteen hours. It turns out she had gastroenteritis. Incidentally, the pharmacy hadn't delivered the medication to the house, as they said they would.

When Mum did pass away, the GP was very helpful in attending the hospital to sign a death certificate to avoid an unnecessary post mortem. The Coroner and GP saw no reason for the post mortem except to satisfy the doctor at the hospital, it does not help the family to be put through this at a very difficult time. I do not think people realise that if a patient has seen their own GP within the last 3 months then they are able to sign a death certificate. When someone is aged over 80 you can ask for a cause of death as 'Old Age'.

We feel there is a lot of room for improvement, especially with relation to communication with patients and carers. There is vast room for improvement with relation to a patient's mental health wellbeing when staying in hospital. Mum was isolated in one room for over three weeks with no stimulation.

In hospital, physiotherapy being offered frequently would speed up a patient's recovery process, however it is not happening. We found that on more than one occasion a doctor would recommend physio, then we would be told it will not start until after the weekend as they do not work at weekends, then the physio would visit on Monday or Tuesday and it would not actually start until the next day. Sometimes a whole week was wasted, and Mum's case was considered quite urgent!"

## 4.2 Hospital Discharge

Healthwatch Croydon has conducted extensive research on the discharge experience of the over-65s at Croydon University Hospital, publishing a report, and hosting a focus group event on 9 February 2016.

We found that solid improvements have been made, such as increased use of advocates, better communication with carers and family members, and use of 'hospital passports' to augment medical records and help facilitate joined-up-care. We also found that agencies would benefit from closer working relationships, so that adequate support is provided, and in a timely manner.

The following case studies illustrate recent experiences:

### 4.2.1 “Difference of Opinion Between the Hospital and the Care Home.”

Mum was in hospital until I could find a care home for her. We were given a brochure, application form for finances, and told by the hospital doctor and social worker to 'do it in two weeks'. I was contacted two days later by the doctor who said Mum's form had not been filled in right, he said the assessment was 'wrong' as he thought Mum needed residential care. The home we chose assessed Mum and turned her down as they thought she needed nursing care. This clear difference of opinion between the hospital and care home wasted five days and I had to take time off for interviews and visits.

Another suitable home was found and an assessment done in three days but they were told Mum had a viral infection and they could not accept her till that was gone. The next day we were told Mum was on her way to the home but the home had not been notified of her arrival, or whether the infection had cleared up. Fortunately the home accommodated her and now everything is fine. It's been really tough and I don't want to go through it again!

### 4.2.2 “What Do We Do Now?”

Dad was discharged from the older people's ward after a long spell, and although we were very pleased to have him back home, we were disappointed that no arrangements for his blood pressure tests (which we understand are essential) were made, and we were given no information. The staff who were present at the hospital said the doctor who cleared his release didn't really tell them anything, or give any instructions. What do we do now?

### 4.2.3 “We Haven't Got Anything in Writing.”

My dad is to be discharged today, but we haven't got any funding for a care package and I'm worried. The hospital say they will help organise a care plan and secure district nursing and palliative care, but this all seems a bit of a rush and we haven't got anything in writing. Call me old fashioned, but these important things shouldn't be done on word-of-mouth alone, as we need to be sure, and have clear recourse if things go wrong.

### 4.2.4 “Mum Can't Get In and Out of Bed, But Deemed Fit to Go Home”

I don't know how the occupational therapist came to the judgement that Mum is ready to go home. She can't get in and out of bed - case in point, she has to be helped in the ward to get into the side chair.

**“Care plans can be tick-box exercises.”**

General Practitioner

#### **4.2.5 “I Fear Mum Will Just End Up Back on the Ward.”**

Mum is being sent home this week but clearly, she doesn't have the mental capacity to be independent. She'd be much better off in a nursing home and I fear that she'll just end up back on the ward.

#### **4.3 Support at Home**

Getting the right level of home support is important, if older people are to stay healthy and out of hospital. We hear that social workers are not always responsive, and that some residents, with 'slightly irregular' issues have not managed to secure any support.

##### **4.3.1 “District Nurses Say It's Not Their Responsibility”**

My 86 year old Mum has advanced arthritis and her left fist is permanently closed tight. This means that it's virtually impossible to cut the nails on that hand - I used to in the past, but now she screams in agony if I move a finger just a fraction. The district nurses say it's not their responsibility to cut nails, and I haven't been able to get it done privately either. Believe me, I've tried all avenues and am willing to pay. So what do we do? Just wait until the situation becomes unbearable and turn up at A&E? I despair.

##### **4.3.2 “We Haven't Heard Back from the Social Worker.”**

Mum was discharged with a care package I don't feel is working. She has dementia and wanders around town without her keys and money. We keep chasing her social worker and have left several messages, but we haven't heard back. She was also sent home from hospital with medication that clearly states 'not to be used at discharge'.

##### **4.3.3 “I'm 76 Myself and Not Able to Care Full Time.”**

My husband had major surgery recently and is being discharged back home with a minimal care package. I can't look after him full-time as I'm 76 myself and not well. How do we get the care package reviewed and how long will it take?

#### **4.4 Allowances and Assessments**

We have heard that carers can be confused about their entitlements and processes, with some experiencing delays due to staff shortages.

##### **4.4.1 “I'm Confused About It.”**

Somebody told me I should be getting a carers allowance, and I never even knew! I care for my 98 year old dad with no financial (or other support), and I'm over 65 myself. I went to Age UK and they gave me some forms, but as I am above 60 I don't meet the criteria. I'm confused about it.

##### **4.4.2 “How Long Do We Have to Wait?”**

I need to get a carers assessment, so went to the Carers Information Centre and they helped me to get the ball rolling with the Council. However, they said the duty social worker is on holiday and we have to wait 8 weeks, just for an assessment. It will then take more time for it to pass through the system. How long do we have to wait? I'm having real trouble getting Mum up and down the stairs, she doesn't mind sleeping in the living room but getting to the bathroom is essential.

**“This week I had to tell my story three times.”**

**Informal Carer**

## 5. Learning from Experience

Based on what we've heard, we have summarised 'key' improvements that may be considered to improve the service in certain areas.

It is the role of Healthwatch to influence the commissioning and delivery of services, therefore our recommendations are not prescriptive, but intended to inspire solutions to the issues that clearly exist.

### 5.1 Hospital Discharge

We found that communication plays a key role in the majority of complaints, whether that is providers not sharing information, patients confused at the point of discharge, or carers and family not involved in decision-making.

#### *Recommendations for Acute Care*

5.1.1 Although communication is everybody's responsibility, there needs to be a clear audit trail of who at the hospital is responsible for arranging discharge, and when.

**Action:** By this time next year, we hope that hospital record-keeping will evidence individual communication requirements alongside actions, so we can be sure that essential information has been communicated, and also trace the causes of any problems. In the case of an 'unannounced' discharge to a nursing home, was it a hospital staff member at fault, or did a home employee receive a message and not pass it on to colleagues? Record keeping will make this clear.

5.1.2 We have heard that instructions on medication (for example dosage) are not always clear, with one family having to 'chase the hospital' for urgent advice.

**Action:** By this time next year, we hope that clear instructions on all medication are provided and checked at the point of discharge.

### 5.2 Support at Home

We have heard that it can be difficult to access support as and when needed, with experiences of delayed, minimal, or no support at all. Care workers do not always let families know if they are late, or not coming.

#### *Recommendations for Adult Social Care and Community Health*

5.2.1 More than one carer has said it can be difficult to reach social workers by phone with messages not responded to timely, if at all.

**Action:** By this time next year, we hope that telephones will be answered more often, and when not, messages may be left that are responded to.

## 5.2 Support at Home (Continued)

5.2.2 Families have told us that care workers who are late, or not coming at all, sometimes do not get in touch.

**Action:** One care worker, arriving late at 11pm, 'caused distress to the elderly resident'. It is common courtesy to keep families and carers updated if arrival times are not met. Care workers should be able and equipped to phone clients whenever necessary.

### *Recommendations for Primary Care and Community Health*

5.2.3 In one case, a daughter has been unable to get her arthritic mother's finger nails cut, leading to deteriorating health and wellbeing for both.

**Action:** By this time next year, we hope that GPs, or Community health services would be able to provide some assistance in cases where a clear health risk exists, that the 'system' is not configured to deal with.

## 5.3 Care Planning

Residents and carers tell us that the health, mental health and social care professions use separate care plans, which are not directly linked, leading to care that is not as holistic as it could be. This also presents a potential obstacle to integrated care.

### *Recommendations for All*

5.3.1 Residents and carers with multiple care plans tell us they are often 'confused'.

**Action:** By this time next year, we hope that some care plans may be 'pulled together'. This has been achieved in other London boroughs (such as Islington), through use of a software package.

5.3.2 Some GPs feel that care plans can amount to 'tick-boxing' (the care plan should be built around the person, not the person around the care plan).

**Action:** By this time next year, we hope that care plans will fully reflect the needs of the individual, incorporating relevant information from carers.

5.3.3 GPs comment that 'it takes several referrals, to various services, to get a patient on one holistic package. This is a burden, and not the best use of our time.'

**Action:** By this time next year, we hope that patients can be placed on more holistic pathways without it being burdensome to referrers. Flexibility around self-referral, or multiple points of access, may increase entry into life enhancing services.

## 5.4 Allowances and Assessments

Carers should know about their rights and entitlements, particularly under the Care Act 2014.

### *Recommendations for Adult Social Care*

5.4.1 When engaging with people, we found that nobody was aware of this legislation, and therefore, not educated on all of their options.

**Action:** By this time next year, we hope that carers are aware of the Care Act, and with it their lawful rights and entitlements. We hope that accessible, easy to read information will be more prominent.

## 6. Looking to the Future - 'Outcomes Based Commissioning for the Over-65s'

Croydon Clinical Commissioning Group (CCG) and Croydon Council intend to commission a single ten-year contract for managing and delivering services for the over-65s who live in Croydon. Other partners include Age UK Croydon, Croydon Council Adult Social Care, Croydon GP Collaborative, Croydon Health Services NHS Trust and South London and Maudsley NHS Foundation Trust.

The aim is to encourage 65-75 year old people, and their carers, to recognise the benefits of having 'information and relationships which complement preventative health and care services'. By integrating health and social care services, we may be better able to 'wrap services around people, based on their individual need'.

This presents a real opportunity for carers, who can potentially benefit from the more personalised support that the cared-for will receive.

On 24<sup>th</sup> February 2016, Healthwatch Croydon was present at a local 'Outcomes Based Commissioning for the Over-65s' event, to look at how services may become more integrated and work more holistically. It was interesting that most people in the room, carers and professionals alike, placed greatest emphasis on care planning.

Among the comments we noted were:

"Are the care plans written for the people, instead of with the people?"

"As a GP I feel that care plans are irrelevant to accessing services. They're tick-box exercises. This is ironic, as care plans were designed precisely to get access to services."

**"Information tends to go off into the ether."**

General Practitioner



“Because the system's not integrated there are too many appointments and I can't keep track.”

“Care plans are only visible to one organisation, it would be better if they could all have access. As a GP I feel it would work better if we had one single system to manage all (multiple) care plans. But this can't be done without technology!”

“Care plans could be joined-up with better use of IT, but confidentiality is a stumbling block that I've fallen over a few times.”

“Care plans lack information on social determinants - living conditions, social networks etc. As a result professionals don't get a holistic view.”

“Community networks are essential in helping people to re-engage with their communities and tackle social isolation.”

“Different professionals get different things out of care plans (people are only interested in certain information). As this is the case, why not have a single plan for health and social care?”

“GPs sometimes don't explain the care pathway and as a result people can 'fall off and give up'.”

“I have three different health and social care plans - wouldn't it be better if there was just one? We should aim for a more seamless system.”

“I wish people would treat me as an individual with services specific to me. I am not a peg.”

“Information governance restrictions are a barrier - as a GP I have to make multiple referrals for a single pathway.”

“Once you share people's information with other agencies it tends to 'go off into the ether' and people have to repeat themselves.”

“Services are working in silos - we need to break down the barriers.”

“The MDT (Multi-Disciplinary Team) are too medically focussed. The focus should be broader.”

“The Multi-Disciplinary Team (MDT) is a good idea as I can get supported to go shopping etc. These takeaways are costing me a small fortune.”

“This week I have had to tell my story three times. If I had hair I'd be tearing it out!”

“We have to get the balance of power between professionals and service users right!”

**“Community networks are essential.”**

**Charity Chief Executive**

“When looking at a person there's much more than just the physical aspect.”

## **7. Glossary of Terms**

BME	Black and Minority Ethnic
CCG	Clinical Commissioning Group
CPG	Croydon Carers Partnership Group

## **8. References**

### **Carers UK (2016) State of Caring 2016**

[www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016](http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016)

### **Croydon Council (2011) Carers Strategy 2011-2016: The Next Steps for Carers in Croydon**

[www.croydon.gov.uk/democracy/dande/policies/health/carers](http://www.croydon.gov.uk/democracy/dande/policies/health/carers)



“I want to stay healthy and active for as long as I can.”

Croydon Resident, 2016