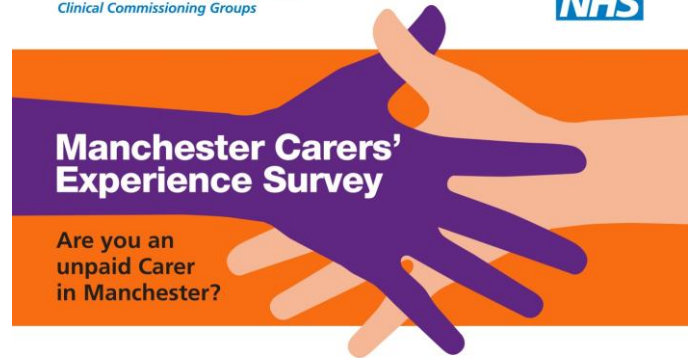




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## What is a Carer?

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.

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son or best friend and just getting on with it.

Carers don't choose to become carers, it just happens and they have to get on with it. If they did not, who would and what would happen to the person they care for?

Carers Trust – [www.carers.org](http://www.carers.org)

## Co-producing this report

A working group of carers and Patient and Public Advisory Group members was established to read through the feedback and develop the recommendations to the Manchester Clinical Commissioning Groups. Carers also chose the poems and pictures used in the report.



Our thanks to Anne McCrystal, Jean Griffin, Sue Sampson, Dave Williams, Gaynor Morgan, Catherine Lowe and Michael Molete.

# Foreword



In Manchester alone, 60,000 carers provide unpaid support for a relative, friend or neighbour. Those carers save the local economy some £854 million annually. So isn't it time that those carers received the support that they need?

Carers make up a large unpaid workforce and yet their contribution is often not seen or understood until the point comes when they break down and the health and social care systems need to intervene often at great expense.

This survey of carers in the city of Manchester which was undertaken by the three Clinical Commissioning Groups in partnership with carers in the city has enabled carers to give voice to issues which hinder them in their caring role. Those same carers also came up with some ideas about how the system can be improved to make it easier for them to both care and be sustained in their caring role.

In an environment where all resources are stretched, we cannot afford to ignore the unpaid contribution made by carers. To do so would place us in a high risk position of having a workforce that collapses. The cost of emergency replacement care would be prohibitive and place additional burden on already overstretched health and social care funding streams. The SMART thing to do is to invest in a workforce that saves our city a great deal of money to ensure that they are supported to be better able to care.

I commend this report for your attention. It makes for both interesting and challenging reading.

Manchester is more than able to show that a ONE TEAM approach really does include carers and reflects the value that our communities put upon them.

A handwritten signature in black ink that reads "D Williams". The signature is written in a cursive style and is enclosed in a thin black rectangular border.

Dave Williams

Chief Officer

Manchester Carers Forum

# Stopping By Woods on a Snowy Evening

by Robert Frost

Whose woods these are I think I know.  
His house is in the village though;  
He will not see me stopping here  
To watch his woods fill up with snow.

My little horse must think it queer  
To stop without a farmhouse near  
Between the woods and frozen lake  
The darkest evening of the year.

He gives his harness bells a shake  
To ask if there is some mistake.  
The only other sound's the sweep  
Of easy wind and downy flake.

The woods are lovely, dark and deep.  
But I have promises to keep,  
And miles to go before I sleep,  
And miles to go before I sleep.

# Actions and Recommendations

## Actions

- To present this report to NHS North, Central and South Manchester CCG boards meetings in July and August 2015
- To develop an action plan from this report that will be monitored by carers and the Patient and Public Advisory Groups
- To share this report with carers living in Manchester
- To share this report with all GP practices in Manchester
- To share this report with the lead commissioner at Manchester City Council to inform the city-wide carers strategy
- To share this report with the Living Longer, Living Better city-wide leadership group to ensure plans for One Team Manchester include integrated support for carers of all ages

## Recommendations

### Communication and Information

- Improve awareness of information on support services, groups and activities available in Manchester to support emotional and physical health and well-being of carers
- Work with Manchester City Council to promote awareness to carers of their entitlement of a carers assessment and rights under the NHS Constitution
- Enable IT systems to share information so carers are not repeating information to multiple services
- Display carers poster in each GP Practice raising awareness to carers about registering their carer status with a practice
- Provide carers information in an accessible format and language to meet the individual carers needs
- Co-produce information resources with carers and community groups
- Invite all carers for their flu vaccinations each year
- Promote use of the existing carers e-bulletins and communications mechanisms to all NHS and social care organisations across Manchester

### Dignity and Respect

- Develop a campaign to raise awareness of carers in Manchester and support they provide to thousands of people each and every day of the year
- Promote recognition of the three way relationship between a carer, patient and a GP and don't let confidentiality become a barrier

### Access to health and well-being services

- Provide flexible appointment times at GP practices to reflect carer's needs and circumstances

- Provide flexible appointment times and choices for hospital visits to reflect carer's needs and circumstances
- Promote the use of innovative ways for carers to contact their GP e.g skype
- Be flexible about home visits for carers and remove age limit
- Provide awareness training of needs of communities living in Manchester to health and well-being staff
- Promote best practice from acute hospital trust work around dementia and carers e.g the "best wishes" card, Central Manchester Foundation Trust and inclusion of carers questions in the Patient Experience Tracker

### **Keeping well**

- To provide annual holistic needs assessment for carers
- To promote self-care resources to support carers to maintain health and well-being
- To signpost new carers for a carers assessment with Manchester City Council
- To promote awareness of services, resources, education and training available to carers to support their emotional health and well-being
- To identify opportunities for peer to peer support from other carers and have ability to share advice, information and resources
- To promote awareness of counselling services in Manchester
- To promote awareness of how carers can get a respite break

### **Support**

- To promote awareness of a carers strategy in hospital trusts
- To promote awareness of support for carers who may remain with a patient in the hospital
- To involve carers in medication reviews for people they care for
- To promote awareness of availability of sitters so carers are able to have respite time

### **Education and Training**

- To provide training opportunities for carers on a range of areas as described in the feedback
- Co-design awareness sessions on the local NHS in partnership with local community groups

### **Equality and Diversity**

- To continue to work with providers of public services across Manchester to implement the monitoring of sexual orientation of service users and carers, to better understand access, experiences and outcomes for LGBT people

- To work in partnership with Manchester City Council as part of the city-wide Manchester Carers Strategy to ensure that older carers get the practical support they need
- To work in partnership with Manchester City Council to ensure that the new duties of the Care Act to develop advice and information is tailored and accessible for older carers, including carers who cannot access electronic resources
- To carry out co-produced work with Manchester City Council, carers and the Third Sector to better understand the views and experiences of different groups of older carers, including carers aged 85 and older, older BAME carers and older male carers
- To carry out co-produced work with Manchester City Council and young carers to better understand their views and experiences

**Skills for Care - Common Core Principles for Working with Carers**



# Partnership working

We worked in partnership with Manchester Carers Forum to co-design and mail out the experience surveys directly to carers on their mailing list. Existing mechanisms and opportunities were used to raise awareness of the survey.

In total 3,000 surveys were distributed with a 319 surveys completed giving a response rate of 11 per cent.

As well as paper copies of the survey being distributed, an electronic link to an on-line survey was also promoted through the following e-bulletins and newsletters including:

- Talking Health monthly e-bulletin
- Manchester Carers Forum fortnightly e-bulletin
- Age Friendly Manchester monthly e-bulletin
- ZEST Healthy Living Network email news
- South Manchester Healthy Living Network email news
- Manchester Community Central e-bulletin

Paper copies of the survey were distributed by community and voluntary sector groups including:

- Manchester Carers Centre
- African and Caribbean Care Group
- Black Health Agency (BHA)
- LGBT Foundation
- Expert Patient Programme, University Hospital of South Manchester

Promotion of the survey also took place at community events including:

- South Manchester Housing Volunteer Fair
- Living Longer, Living Better Engine Room event, Levenshulme
- Central Manchester Foundation Trust Annual Members meeting
- Greater Manchester Personal Health Budget Peer Support Group meeting (budget holders from across Manchester)
- Mellands High School Carers Event, Gorton
- South Manchester CCG GP Listening Event, Wythenshawe Forum
- South Manchester CCG Information stall on Northenden Market
- Miles Platting, Ancoats and Newton Heath Age Friendly Manchester locality launch
- Cheetham and Crumpsall Health and Well-being Forum



- 10 copies of the survey were mailed out to each GP practice in Manchester and electronic information shared to raise awareness of the survey to their Patient Participation Groups, via their websites and within their practices.
- Awareness information about the survey and the online link was also shared amongst staff in the Directorate for Children and Families at Manchester City Council for sharing with carers.
- Manchester Learning Disability Partnership Carers' Care Manager sent surveys out and took copies along to visits to share with carers.
- The Admiral Nurse Service at Manchester Mental Health and Social Care Trust also gave out the survey to clients.

As well as using the feedback from this survey to inform the recommendations, we also reviewed recommendations from other carer experience surveys and reports which had taken place in Manchester and nationally at the same time.

This work included:

- The LGBT Foundation – [State of the City for Manchester's Older Lesbian, Gay and Bisexual Communities](#)
- Somali Adult Social Care Agency (SASCA) – Report on the Somali carers in Manchester
- Central Manchester University Hospitals NHS Foundation Trust – Supporting carers of people with dementia
- Age UK – Caring into later life, the growing pressure on older carers
- Carers UK – State of Caring 2014
- Manchester City Council – Development of a Manchester All-age Disability Strategy consultation feedback

# Survey Responses

## 1. How many hours a week do you care for the person you look after?

311 carers answered, 8 skipped the question

	Response %	Response numbers
• 50+ hours	57.88%	180
• 1-19 hours	16.72%	52
• 20-34 hours	13.50%	42
• 35-49 hours	11.90%	37

## 2. What is your paid employment status?

311 carers answered, 8 skipped the question

	Response %	Response numbers
• Not in paid work	34.41%	107
• Retired	28.30%	88
• Work full time	19.61%	61
• Work part-time	13.18%	41
• Self-employed	1.93%	6
• In education (full/part-time)	1.29%	4
• Volunteer	1.29%	4

## 3. Who do you care for?

303 carers answered, 16 skipped the question

	Response %	Response numbers
• Spouse/partner	31.68%	96
• Son/daughter	29.37%	89
• Parent	28.05%	85
• Other relative	3.63%	11
• Friend/Neighbour	2.31%	7
• Brother/Sister	1.65%	5
• Both son/daughter and a parent	1.65%	5
• Grandparent	0.99%	3
• Grandchild	0.33%	1
• Partner (now passed away)	0.33%	1

## 4. Do they live with you?

299 carers answered, 20 skipped the question

	Response %	Response numbers
• Yes	72.91%	218
• No	27.09%	81

## 5. How old are they?

302 carers answered, 17 skipped the question

	Response %	Response numbers
• 35-64	28.81%	87
• 75-84	18.87%	57
• 85+	15.89%	48
• Under 18 years	12.58%	38
• 19-34	11.92%	36
• 65-74	11.92%	36

## 6. What is their main illness or disability?

255 carers answered, 64 skipped the question

	Response %	Response numbers
• Physical Disability	18.84%	55
• Mental Health	16.44%	48
• Frail or Elderly	15.41%	45
• Dementia	14.38%	42
• Learning Disability	11.99%	36
• Autistic Spectrum Disorder	9.93%	29
• Stroke	3.42%	10
• Cancer	2.40%	7
• Parkinson's	2.05%	6
• Respiratory	1.03%	3
• Cardiac	1.03%	3
• Sensory Impairments	0.68%	2
• Epilepsy	0.68%	2
• Chronic Fatigue	0.34%	1
• Brain Injury	0.34%	1
• Multiple Sclerosis	0.34%	1
• Fibromyalgia	0.34%	1

### Additional illness or disability included:

- Mental health issues including anxiety disorders,
- Diabetes
- Cardiac issues
- Chronic Kidney disease
- Dementia but not yet diagnosed
- IBS
- Physical disabilities
- Chronic Obstructive Pulmonary Disorder (COPD)
- Frail and elderly
- Sensory impairments including hearing, speech and visual
- Arthritis
- Stroke
- Spinal cord compression
- Lung problems
- Multiple sclerosis
- Learning disability
- Down's syndrome
- Tumours
- Motor Neurone Disease
- Polycythaemia rubra vera (PRV)
- Cerebral Palsy
- Myeloma
- Marfans syndrome
- Short term memory loss
- Stoma bag
- Suprapubic catheter
- Muscle weakness
- Drug and alcohol problems
- Complications from back surgery
- Aortic aneurism

## 7. Is there any training or support you think should be offered to carers?

254 carers answered, 65 skipped the question

	Response %	Response numbers
<input type="radio"/> Yes	72.05%	183
<input type="radio"/> No	27.95%	71

### Carers identified the following training:

- **Self Care**
  - How to make time for yourself
  - Relaxation skills
- **Mental health and well-being**
  - Coping strategies for the inevitable frustration, emotions and anger you feel at times
  - Stress management
  - Dementia awareness
  - Autism awareness
  - How to deal with someone with mental health issues
  - Bereavement counselling
  - Mental Health Act
  - Counselling
  - Psychological support
  - Mindfulness training
  - How to cope with challenging behaviour
- **Exercise and Physical Activities**
  - Tai Chi
  - Health Walks
  - Chair based exercises
  - Relaxation classes
- **Life Skills and Relationships**
  - Conflict resolution
  - Education on budgeting
  - IT training – basic skills needed
  - Building self-esteem and confidence
- **Caring for someone**
  - Moving and handling / Lifting and manoeuvring
  - How to deal with a long term illness
  - Basic first aid skills including CPR
  - Medication awareness and information
- **Clinical care**
  - Peg feeding
  - Catheter care
  - Changing dressings
  - Stoma care
  - Sensory training
- **Information**
  - On where to find practical help and support
  - How to access care home services
  - Respite, breaks and short trips
  - Signposting to accessible activities and discounts where applicable
  - Advocacy
  - Evening and weekend activities and support for carers
  - Peer support, where it is and how to access it

- On specialist play-schemes, where are they and how to access them
- On specific health conditions so carers know what to expect
- Where carers groups are held across the city
- How to get a blue badge
- How to get adaptations for the home
- How to talk to a parent about ageing and their changing needs
- About when someone dies and funeral planning
- What to expect from public sector organisations
- Legislation on disability
- Where to meet other carers
- Where to find emergency help
- On benefits, which ones as a carer I am entitled to, where and how to apply for it
- **Communication**
  - Basic communication skills
  - 24/7 helpline for carers living in Manchester

***“75% of carers said it was hard to maintain relationships and social networks because people do not understand the impact that caring has”***  
***Carers UK, State of Caring Report, 2014 (n4924 carers)***

## 8. Have you been diagnosed with any of the following conditions?

236 carers answered, 83 skipped the question

	Response %	Response numbers
• High Blood Pressure	38.98%	92
• Depression	36.86%	87
• Lower Back Pain	34.32%	81
• High Cholesterol	34.32%	81
• Anxiety	27.97%	66
• Asthma	22.03%	52
• Diabetes	19.49%	46
• Chronic Pain	18.64%	44
• Angina	5.08%	12

Other conditions included:

- Cancer (Prostate, Breast and Skin)
- Fibromyalgia
- Multiple Sclerosis
- Lupus
- Chronic Fatigue Syndrome
- Post Traumatic Stress Disorder
- Chronic Obstructive Pulmonary Disorder
- Mental Health (Bi-polar and depression)
- Parkinson's
- Arthritis
- Coeliac disease
- IBS
- Heart disease (atrial fibrillation and ischemic)
- Thyroid issues
- Stroke
- Ulcers
- Blood clots
- Hernia
- Sciatica
- Breathlessness

***"58% of carers have reduced the amount of exercise they do since they started caring"***

***Carers UK, State of Caring Report, 2014 (n4924 carers)***

## 9. Do you feel that your medical condition has become worse since you started caring for someone?

274 carers answered, 45 skipped the question

	Response %	Response numbers
• Yes	57.66%	158
• No	21.17%	58
• Unsure	21.17%	58

## 10. Have you experienced any of the following since becoming a carer? Please tick all that apply.

287 carers answered, 32 skipped the question

	Response %	Response numbers
• Anxiety/stress	77.00%	221
• Exhaustion/tiredness	75.26%	216
• Lack of sleep	64.46%	185
• Migraine/headache	36.93%	106

Other comments included carers experiencing:

- Resentment, feeling sorry for oneself, weeping
- All of the above, and lost my self-identify. Can't work due to caring role
- Tearfulness, broken sleep, sense of 'loneliness' (5+ years as a carer)
- Lack of sleep due to neglect of my father in a nursing home while my grandmother gets better care in her home
- Lots of colds and minor illnesses
- Aches pain, foggy head
- Impatience, but the support I receive does help
- Been a carer all my life, even lost my hair
- Depression, breathlessness
- There are times my son puts me under a lot of stress
- High blood pressure, I think related to persistent high level of anxiety re partner's risk to himself over many years
- Guilt
- All of the above, and lost my self-identify. Can't work due to caring role
- I find it difficult to do housework, washing etc, and give the full care to my husband. I am elderly which contributes
- Health related issues - shingles due to stress
- Anger, flu like symptoms
- Feelings of uselessness

## 11. Do you feel that caring for someone has contributed to these conditions?

295 carers answered, 24 skipped the question

	Response %	Response numbers
• Yes	74.24%	219
• Unsure	16.95%	50
• No	8.81%	26

## 12. Have you sought help for managing these conditions?

284 carers answered, 35 skipped the question

	Response %	Response numbers
• Yes	67.81%	192
• No	32.39%	92

*"73% of carers feel more anxious because of their caring role"*

*Carers UK, State of Caring Report, 2014 (n4924 carers)*

## 13. If you responded no, please explain why?

- Mentioned once to GP, his reply was that he would support me in requesting extra hours covered by PA or carer
- It is extremely hard to fit appointments around my two sons as they have numerous appointments, plus mum's cancer treatments/appointments, I come last on the list!
- Never have the time spend more time dealing with medical appointment for son, and his needs, I can't afford to be ill he relies on me to keep things together, and constantly battle for rehab for him
- Difficulty in getting appointment at GP's/that fits in with work and caring for my daughter... no time!!
- Haven't got time between work and caring
- Not got time I just try to get on with it
- Confided and talked to family members
- Just feel it's all part of looking after someone who is seriously ill/disabled
- Child has autism, and sometimes wakes for periods during the night and needs looking after
- No time to get help
- Due to work, and I talk to family members
- But have had tablets from doctor for migraine, do not wish to have tablets for stress
- It has nothing to do with caring for my grandmother. It has to do with the lack of care of my father. The small amount of family to look after him along with carers would have done a better job
- Just tend to cope
- Just soldier on
- Too busy
- I have recently spoken to my church minister who is providing support. Where would I seek help? Who can stop my dad ringing me at all hours? Being lonely and constantly asking / expecting me to be there/take him out? I try to preserve space for me but sometimes am so weary I don't have the energy to summon up what it takes to convince him I'm saying no. I spend so much time at work organising his med care / other stuff I don't make time to be able to make appointments for me.
- I don't want to be prescribed anti-depressant drugs.
- Too busy looking after my mother and husband who I also am a carer to
- Lack of time and energy is the main reason
- Goes with the territory
- Don't feel it is appropriate
- The problem is caused by lack of communication at the nursing home



- Have managed to recognise when I am becoming stressed or tired so I have time to myself
- I am aware of the stress involved and have evolved ways to cure, for example have hour walks quiet periods in quiet places
- I have chosen to use herbal remedies such as St Johns and it works
- Apart from GP = medication + physiotherapy, not aware of any help available
- I have hobbies that help etc. walking gardening and reading
- No time to. I work full time, part time and have a six year old. On top of this I am caring for my 23 year old son who lives with my 74 year old mother... No time to see GP about me
- I do not want to rely on medication
- No point doctors. Just fob people off
- Don't want to bother anyone, just get on with it
- I've made appointments but always cancel them I am not good with doctors
- Managed by medication
- I am worried that if they find anything wrong with me I may be hospitalised and there will be no one to look after my wife
- I can do it myself I have been looking after my mum for 9 years
- Who can help with anxiety?
- Conditions due primarily to cuts in day provision for my son meaning I have to battle for everything
- Because my G.P would probably just prescribe anti - depressants - I self-medicate with St. Johns Wort herbal tablets
- I have periods of anxiety - having to deal with my Gran's care needs and communicating with doctors and social workers
- I don't know where to go, who would understand
- Physical symptoms of anxiety?/ a strange sensation raising through my body. Has happened several times. GP advised four days' rest. Also have a sick daughter living abroad
- I have sought help - no help has been forthcoming
- No doctors will help
- Need to concentrate on husband, no time for me
- Pointless seeking help. Life goes on
- The support I am offered is not enough so my health deteriorates
- Goes with the job
- Have no time as am a single parent as well as a carer
- Don't like to be a burden to others, prefer to just get on with it
- Only gone GPs for medicine
- I have tried
- I just think a GP would tell me to relax more and go to bed earlier
- Because I like to do every by my way and we are Iraqi we have different ways to eat, talk etc
- Old age is natural, especially when married for nearly 60 years
- I am able to cope myself
- But to no effect, I am getting no help, our care is a civil matter, my son, entire family being trapped
- Anxiety and stress - talk to a coach. Headaches caused by stress which usually are in the morning, and cause sleeplessness/restless sleep - using natural remedies to relax more at night

- Where do you go? The answer to lowering stress levels is to avoid or lessen the situation. My life is the situation.
- It is extremely hard to fit appointments around my sons as they have numerous appointments, plus mum's cancer treatments/appointments. I come last in the list!
- Feel I should just get on with it. This is what happens when we get older, it's inevitable.
- I have just done my best, not seen anybody or heard from social services for over 6 years in looking after my wife in home, a poor response, no interest shown.

#### 14. On a scale of 1 to 5 (1 being dissatisfied and 5 being very satisfied) how satisfied are you with your own health?

296 carers answered, 23 skipped the question

	Response %	Response numbers
• 3	46.96%	139
• 4	29.95%	62
• 2	16.22%	48
• 1	8.45%	25
• 5	7.43%	22

#### 15. What do you think would improve your health as a carer?

276 carers answered, 43 skipped the question

	Response %	Response numbers
• Respite/break	56.16%	155
• Information on services, rights and benefits	50.72%	140
• Annual health check	43.84%	121
• Easier access to my GP	39.49%	109
• Counselling support	39.13%	108
• 24 hour helpline support	27.54%	76

#### Other comments from carers included:

- Nothing. Having been informed that J is on maximum medication, and that any further TIAs will damage her further. I am frightened to leave her
- I know what I should do, e.g. diet, exercise, 'me' time, but it is impossible with my caring role. I eat on the go
- I have found professionals who have some understanding of my role, and acknowledge realities, help me to cope on a long-term basis, e.g. regular meetings with known GP
- waiting for knee operation for over 8 months
- GP is always busy up to 2 weeks for appointment
- I don't think counselling would help. My father died 1<sup>st</sup> of October, its December now. I feel no different from the first day he took ill with sepsis for a second time
- Help for my child to reduce the impact of his disability
- Flexible work hours or unpaid leave at times of crisis
- More direct care support
- To make sure I'm doing everything ok
- Day services for my son to be back as they were before cuts day centre closed
- More financial help
- Easier access to my Gran's GP
- It has improved since my mum moved into 24 hour cover sheltered house (not care home)
- Class or specific advice on manual handling and early access to adaptations

- Again this needs to be offered in a way that does not disrupt my mum's routine as it makes it harder for me to resettle also need more hours
- A less useless care company that isn't using us as a cash cow!
- Death
- Want a social worker to be there for us
- Please consider carers who have other children as well
- need help to get fitter and healthier - sure I will cope better
- I do have access to all these other services from Social Services
- More support for my spouse
- Some actual interventions for my child.
- More money equality
- Help to have some time to myself
- I know what I should do, eg diet, exercise, 'me' time, but it is impossible with my caring role. I eat on the go
- I have carers who come to the home. They give body wash only and turn patient over. This is all they do. I pay full cost for this service
- Someone to talk to, having time for myself
- Waiting for knee operation for over 8 months
- A fair benefit for what we do!

## 16. Which GP practice are you registered with?

The responses have been themed into the individual Clinical Commissioning Group GP patches and localities:

262 carers answered, 57 skipped the question

	Response %	Response numbers
S = Burnage, Chorlton and Didsbury	10.50%	25
N = Higher Blackley, Harpurhey and Charlestown	10.50%	25
N = Ancoats, Clayton and Bradford	10.50%	25
S = Wythenshawe	10.08%	24
C = Gorton and Levenshulme	9.66%	23
N = Miles Platting, Newton Heath, City Centre, Moston	9.24%	22
S = Northenden and Wythenshawe	8.82%	21
C = Chorlton, Whalley Range and Fallowfield	8.82%	21
S = Fallowfield and Withington	5.88%	14
C = Hulme, Moss Side and Rusholme	5.88%	14
N = Crumpsall and Cheetham	5.88%	14
C = Ardwick and Longsight	4.20%	10
Greater Manchester GP Practices	10.08%	24

## 17. Is your GP practice aware that you are a carer?

277 carers answered, 42 skipped the question

	Response %	Response numbers
• Yes	60.65%	168
• Unsure	24.19%	67
• No	16.16%	42

## 18. Is the person you care for registered at the same GP practice as you?

279 carers answered, 40 skipped the question

	Response %	Response numbers
• Yes	75.99%	212
• No	24.01%	67

## 19. Has the GP practice recorded that they have a carer?

277 carers answered, 42 skipped the question

	Response %	Response numbers
• Unsure	55.23%	153
• Yes	32.13%	89
• No	12.64%	35

## 20. Does your GP practice offer you appointments that meet your needs as a carer?

281 carers answered, 38 skipped the question

	Response %	Response numbers
• Yes	38.43%	108
• No	35.59%	100
• Unsure	25.98%	73

## 21. During appointments, does your GP or nurse acknowledge that you are a carer?

271 carers answered, 48 skipped the question

	Response %	Response numbers
• No	45.02%	122
• Yes	34.69%	94
• Unsure	20.30%	55

*"49% of carers feel that society does not think about them at all"*

*Carers UK, State of Caring Report, 2014 (n4924 carers)*

## 22. How do you think local NHS services (GPs, Hospitals, dentists, pharmacists and opticians) might better meet your needs as a carer?

### Access to health services

- Open at weekends Longer opening hours on weekdays Not having to wait excessive time for an appointment
- By being more flexible at the moment I manage to keep any appointment for my husband
- Example, flu jab nurse comes to flat for J, I have to make appointment. More resources for community. We all know this won't happen
- Arranging weekend appointments
- The time of the appointments
- Give us appointments that fit our needs, not what's available
- Home visits - get an idea of home life

- I am fortunate I am fast tracked with my GP, but dentists, opticians etc need to keep a record if the patient is a carer and appreciate that they have had to find a sitter to keep an appointment
- Yes. More speedier service. i.e. quicker appointment times
- Trying to find suitable times when you can leave the person you care for, and arranging for someone to stay with them if possible
- More flexibility with appointments regular check up's access to support for carers - counselling
- Book a time for both of us same hour!
- They should accommodate to carers needs eg. appointment when required and the time that suits the carer
- More prompt notification of test results. Provision of appointments at a time I can get there without taking too much time off work.
- Time to discuss your needs
- Convenient appointments at short notice
- For me it's having access to appointments early in the day or early evening to accommodate full-time work. To be fair I think is possible had I time to focus on making one. The practice did have a ring on the day appointment arrangement, which I think has changed but it's so long since I went I'm not sure. When I do go I tend to have a shopping list - so a longer appointment would be useful. I'm unsure what being registered as a carer means in terms of the impact for me?
- Be more adaptable where appointments are concerned and flexible in terms of 'rules and regulations'
- One thing would be that we have a permanent doctor at our surgery. Every time I go it's a different doctor
- I have to take an appointment the surgery offers - can't choose. It is essential for health professionals to visit the home. I need podiatry and can't always keep appointments. Dental appointments needed opticians. I have had to forgo various appointments because I have to be all day looking after my husband. There is no freedom from being sole carer. I am sole carer.
- Saturday opening for GP surgery would help enormously
- Unfortunately it can be very difficult to get an appointment at my GP surgery that isn't at least a week away. I can't always get to the doctors in person to try and make an appointment and the phone is always engaged. This puts me off making appointments for myself.
- Be more flexible, over appointment and cancelling at short notice
- Acknowledge the difficulties or arrangement appointments, ie finding someone to care for the patient in my absence
- My GP is only accessible downstairs. The doctor that we used to see is upstairs, so I can't see her with my daughter. We have been told that she can only see the doctor who has a room downstairs.
- By offering appointment times appropriate to the person asking for them, ie not in the middle of a normal working day when the carer works full time
- I feel we are extraordinary and fortunate in living where we are. Our GP, hospital have provided us with superb service to us during the many times we had to use the over the past 10 years

### **Meeting our needs as carers**

- Listen to our needs and expertise in caring for these people
- Be more flexible for carer. Maybe do home visits if carer unable to travel or visit because of child or other child

- GP - had to wait too long for an appointment. I don't feel as if I am treated as a carer. I feel that we should be listened to and not suppress and dumb us down. It is so painful. Please allow me to voice my story and obtain the help we need
- Try listening, when you explain behaviour problems due to head injury, then maybe life would be easier all round, and my son wouldn't be treated as a trouble maker and asked to leave accident and emergency department
- Generally I have received good support. Continuity of personnel is important
- I've had no need for any of the above services whilst being a carer so unsure
- Firstly to identify that I am a carer. Offer more home visits for the elderly who I care for.
- Easier access to my GP with appointment to suit my caring duties and not having to book weeks ahead with unrealistic times
- Just give as much help and advice as possible
- Awareness of multiple issues that face carers
- Respect and being treated as a partner not a nuisance. However my GP surgery is really good these comments apply to other services, especially those that treat my son and mother
- GPs, dentist, opticians and general hospital care are good. I am very concerned that we have no help from mental health services
- I have to see a doctor every time I need a repeat prescription for anti-depressants, this is difficult as I don't have any spare time. My condition is caused as a direct result of my son's illness and therefore is not going to change. Why can I not have repeat prescriptions and just have a review every 6-12 months?
- I think it causes more stress and anxiety when you have to 'fight' for the treatment access to support and help. When you initially express your concerns about your child/person caring for a list of service and support should automatically be provided
- They need to understand that when an appointment is made, you cannot always make it, due to your caring role, and not make you wait weeks to get another, and not to send you to far out hospitals, if all appointments could be made for one day that would be great, everything done at once, instead of coming and going
- Given the pressure on all these services I am happy with what I get - except for the difficulty of getting respite breaks
- Take our responsibility as a carer into account when making an appointment and helping us when making calls about appointments have a system that can deal with someone not knowing their address date of birth etc.
- Hospitals - need greatly improve support services for those carers who stay with the person they care for when they are inpatient, by providing as a minimum reclining chairs at side of the bed
- Ask if I am a carer at appointments. Link my records to my sons so they might know what is going on.
- Not sure. Better recognition of role of carers as somewhat experts in patients condition and as a first responder in deteriorations

## **Communication and Information**

- By listening more and helping me express my needs/feelings more clearly. majority of the time I feel I haven't even scratched the surface of the problem after I see a health professional
- Not sure what is available
- By acknowledging and taking into account you are a carer
- I rarely visit GP now due to lack of the concentrating on my husband's care it might help if the surgery phoned to ask how I am occasionally
- Better communication between NHS services not very good at present

- I'm sure that they are trying their best, all I ask for is good manners and a smile
- Acknowledge and respect the fact you are a carer
- Listen more to us, every time I ring up the phone goes to answer phone
- GP just want to know why you are here to see them. you get very little time to explain your issues, I feel very uncomfortable because the doctors attitude changes after 5 minutes
- More training for the receptionists. Their attitude can be offensive, but if challenged it is put back on the patient
- Offering more support in diagnosis and treatment for those who are being cared for and understanding that not all physical disabilities are visible
- By informing me more of their services
- Should indicate carer on appointment cards.
- I think they already support me really well. Especially the Macmillan drop-in at Wythenshawe hospital. I don't think enough drop in centres like this exist.

### **Support for carers**

- More support groups within 1 mile of home more regular contact from sound services
- Yearly health check faster hospital appointments if a delay in clinic to get pushed up the waiting queue as someone at home realise on me for support 24/7
- My main unmet need is for time to spend with friends. More daytime activities with support from others for my spouse would improve his quality of life and hence mine. He needs more help with motivation than I can give.
- Regular health checks for carer awareness of referred to carer support organisation services
- In home counselling and 24 hour helpline
- Help with transport. We have no car.
- Asked for counselling told the waiting list is to long
- Confidential regular checks with the carer, to make sure that everything is going ok because carers get wrapped up in caring and often forget about themselves
- Easier access to appointments and stop charge for the emergency call out alarm
- At present I attend a carers meeting every 2 months. It is held at Florence House, the above GP practice and advice, talks etc are given, and a good circle of people to talk to
- One point of contact - services coordinated
- More understanding of autism
- Evening sitting service once a week would be good
- More advice support. More follow up and NHS works actually listening to what I say. I know my mum and I know how different she is now.
- Provide day centres for carers to take a break away from home
- Respond and understand the needs of carers and the stress and pressures that are placed upon us. Have more available access to appointments that fit into our difficult times of caring. As carers we may not have someone to look after our dependents to attend appointments.
- Less waiting time. Less patients, extra opening times. We need recognition as a carer, ie maybe a card with a photo and a number. It would make things a lot easier and less embarrassing.

### **Commissioning of services**

- Commission services that help children with disabilities rather than just diagnose them. Diagnosis assumes schools will provide intervention but they don't. This is one of the largest causes of exhaustion.

- Listen more to us. the service is appalling every time I phone the Rawnsley building it goes to answer-phone
- Offer some interventions to help my child. Commission some interventions to help my son. Provide some interventions to help my child.

### **Confidentiality**

- I know there are confidentiality issues but my husband is a unreliable witness about his health and it would be good to be able to discuss him without him being there sometimes
- Intelligent application of confidentiality
- My husband won't see a doctor when ill. I should still be able to go doctors for him and explain the symptoms and work out a plan rather than suffer at home and refuse doctor help
- That they keep my name next to my hubby's on file so I don't have to get stressed when I phone for information
- By understanding that I know my daughter's needs health wise physically and mentally





# Demographic Information

## Carers Postcode

271 carers shared the first 3 digits of their postcodes.

<b>Postcode</b>	<b>How many?</b>	<b>CCG GP Patch or Locality</b>
<b>North Manchester CCG</b>		
M1 and M40	25	Miles Platting, Newton Heath, City Centre and Moston
M8	14	Cheetham Hill and Crumpsall
M9	24	Higher Blackley, Harpurhey and Charlestown
M11	11	Ancoats, Clayton and Bradford
Total = 74		
<b>Central Manchester CCG</b>		
M12	12	Ardwick and Longsight
M13 and M15	10	Hulme, Moss Side and Rusholme
M14 and M16	30	Chorlton, Whalley Range and Fallowfield
M18	16	Gorton and Levenshulme
Total = 65		
<b>South Manchester CCG</b>		
M19 and M20	40	Burnage, Chorlton and Didsbury.
M20 and M21	41	Fallowfield and Withington / Northenden and Wythenshawe
M22	31	Wythenshawe
Total = 109		
<b>Greater Manchester CCGs</b>		
Gtr Mcr	23	Bolton, Oldham, Trafford and Stockport

## Jenny Joseph's "When I Am an Old Woman I Shall Wear Purple"

When I am an old woman I shall wear purple  
With a red hat which doesn't go, and doesn't suit me.  
And I shall spend my pension on brandy and summer gloves  
And satin sandals, and say we've no money for butter.  
I shall sit down on the pavement when I'm tired  
And gobble up samples in shops and press alarm bells  
And run my stick along the public railings  
And make up for the sobriety of my youth.  
I shall go out in my slippers in the rain  
And pick flowers in other people's gardens  
And learn to spit.

You can wear terrible shirts and grow more fat  
And eat three pounds of sausages at a go  
Or only bread and pickle for a week  
And hoard pens and pencils and beer mats and things in boxes.

But now we must have clothes that keep us dry  
And pay our rent and not swear in the street  
And set a good example for the children.  
We must have friends to dinner and read the papers.

But maybe I ought to practice a little now?  
So people who know me are not too shocked and surprised  
When suddenly I am old, and start to wear purple.

# Monitoring Information

## Sex

276 carers answered, 43 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
Female	73.55%	203
Male	26.45%	73

## Gender

Is your gender identity the same as the gender you were assigned at birth?

260 carers answered, 59 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
Yes	99.23%	258
No	0.77%	2

## Age

273 carers answered, 46 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
46-60	36.26%	99
61-80	33.70%	92
36-45	15.75%	43
26-35	7.33%	20
81+	5.49%	15
18-25	1.47%	4

## Disability

264 carers answered, 55 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
Yes	50%	132
No	50%	132

## Marital Status

273 carers answered, 46 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
Married	54.21%	148
Single	34.80%	95
Life Partner	7.33%	20
Widow	2.20%	6
Civil Partnership	1.47%	4

## Ethnicity

271 carers answered, 48 skipped the question

	<b>Response %</b>	<b>Response numbers</b>
White British	80.07%	217
Asian or British Asian (Pakistani)	5.17%	14
Black or Black British (Caribbean)	4.43%	12
Black or Black British (African)	2.21%	6
White Irish	1.48%	4
White (other)	1.48%	4
Asian or British Asian (Indian)	1.48%	4
Mixed (White and Black African)	1.11%	3
Mixed (White and Black Caribbean)	0.74%	2
Mixed (White and Asian)	0.74%	2

Asian (East African Asian)	0.37%	1
Black (other)	0.37%	1

### Religion/Faith

262 carers answered, 57 skipped the question

	Response %	Response numbers
Christian (including all Christian denominations)	62.21%	163
No religion	26.72%	70
Muslim	7.25%	19
Jewish	1.53%	4
Buddhist	1.15%	3
Hindu	0.76%	2
Sikh	0.38%	1

### Sexual Orientation

260 carers answered, 59 skipped the question

	Response %	Response numbers
Heterosexual	94.23%	245
Lesbian	1.92%	5
Gay	1.92%	5
Bisexual	1.92%	5



## Useful Information

Manchester Carers Forum

<http://www.manchestercarersforum.org.uk>

0161-819-2226

Manchester Carers Centre

<http://www.manchestercarers.org.uk>

0161-272-7270

ZEST Healthy Living Network

[www.facebook.com/ZestManchester](http://www.facebook.com/ZestManchester)

0161-234 -3715

South Manchester Healthy Living Network

<http://www.mhsc.nhs.uk/services/wellbeing-services/south-manchester-healthy-living-network.aspx>

0161-217-3667

Healthy Me, Healthy Communities

<http://www.healthymehealthycommunities.co.uk>

07913-540680

Didsbury Good Neighbours

<http://www.didsburygoodneighbours.org.uk>

07749-504298

Later Life Living

<http://www.laterlifeliving.co.uk>

07731-795418

Alzheimer's Society Manchester

[http://www.alzheimers.org.uk/site/custom\\_scripts/branch.php?branch=true&branchCode=12646](http://www.alzheimers.org.uk/site/custom_scripts/branch.php?branch=true&branchCode=12646)

0161-342-0797

Carers UK

<http://www.carersuk.org>

0808-808-7777

Talbot House

<http://www.talbot-house.org.uk>

0161 203 4095

## Websites

Mental Health in Manchester

<http://www.mhim.org.uk>

Choose Well Manchester

<http://www.choosewellmanchester.org.uk>

NHS Choices

<http://www.nhs.uk>

## Plan for a care emergency – Manchester City Council

Over 95% of carers worry about what would happen if something unexpected happened that meant they were unable to care. Because of this, Manchester has a number of services to give carers peace of mind.

- All carers can get their own emergency card. For more information speak to Contact Manchester on 0161-234-5001
- Carers can access the emergency plan via a Carer's Assessment. To request an assessment call the Contact Service on 0161-234-5001