

Report on the Consultation: 'How Can we Improve Support for Carers?'

Background

Healthwatch Wandsworth became aware of the Department of Health's plan to develop a new strategy for carers; addressing their needs and how more can be done to support them. Healthwatch Wandsworth launched a survey to gain insight into carers' current lives, including issues around their own health and financial concerns, and what support they need to help them live well whilst caring for a family member or friend. We wanted to measure the current experiences of local residents in **Wandsworth** and their satisfaction with the current support services available, with a view to measuring current practice against the new proposed strategy.

The consultation was open from 9th June 2016 until 22nd July 2016.

Findings

22 respondents completed the survey. A sample of the questionnaire can be found in Appendix A. The survey was used at outreach sessions in Wandsworth, at the following community based organisations and events:

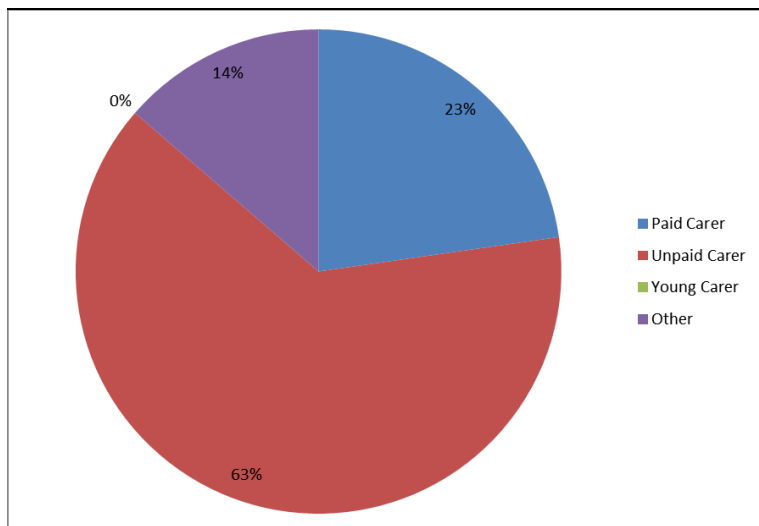
- The Wandsworth Carer's Event as part of National Carer's week
- The Wandsworth Get Active Festival
- The Get Set Go event held by Wandsworth Council and South Thames College
- Wandsworth Carer's Centre

A mixture of open and closed questions were used to draw out people's experiences, thoughts and suggestions, through which we could draw conclusions about the experiences of carers in Wandsworth.

We also held a group discussion with 6 carers at the Wandsworth Carer's Centre, using the toolkit from the Department of Health as a prompt to gather their views. The discussion unearthed more qualitative and detailed feedback and highlighted key areas of support and information that the carers felt was needed. Answers from this discussion can be found in Appendix B.

As a starting point, we wanted to understand the current situation for our respondents as carers in the borough. The response to this question would not only provide an idea of the type of carers in the borough requiring support services, but could also give insight into understanding later answers and suggestions for services in the locality.

Question 1: Are you a paid carer, unpaid carer, young carer or other?

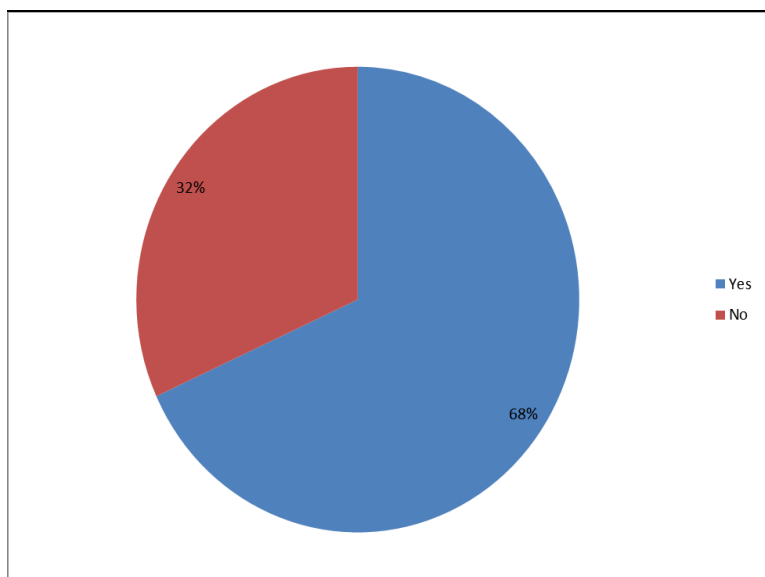


The chart demonstrates that the overwhelming majority of people surveyed were unpaid carers (63%), though almost a quarter (23%) were paid and a few identified themselves as ‘other’. This suggests that the personal circumstances for carers in the borough is varied and, as such, their needs for services will also vary. Some are paid carers and therefore have formal financial support for their role but many are unpaid and will face different challenges because of this.

Our discussions with carers at the Wandsworth Carer’s Centre specifically highlighted the issue of meeting the financial needs of individuals, with many comments on difficulties around the suitability of direct payments and the subsequent burdensome paperwork.

We then wanted to establish whether carers were aware of the current support services available in Wandsworth, which would give an indication of the reach of current services and whether they were likely to be utilised by those that most needed them.

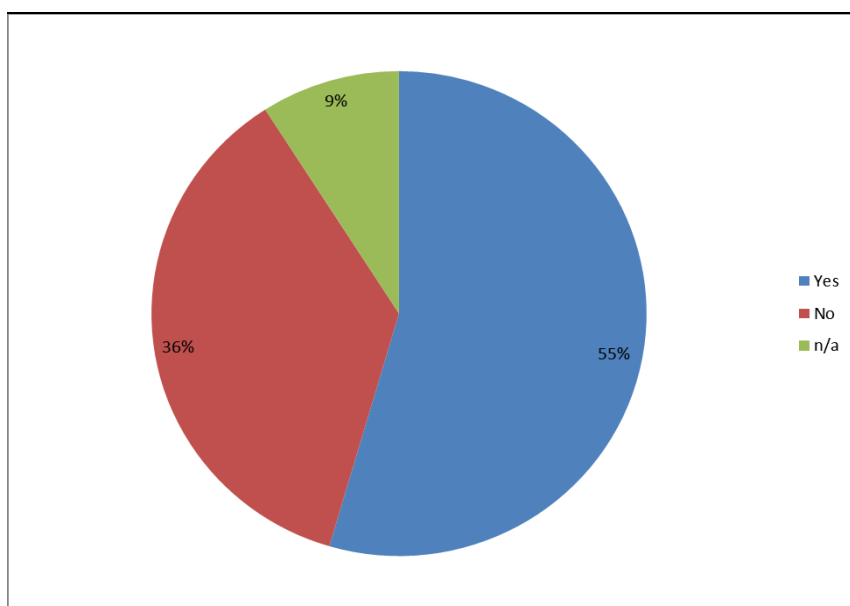
Question 2: Have you received information and advice on the support services that are available for carers?



As the chart shows, the majority (68%) had received information about the services available to them as carers, but a significant number (32%) hadn't. This suggests that perhaps there are carers in the borough who are not aware of the support available to them and who will not be using such services as a result. Therefore, greater publicity or promotion of available services needs to be encouraged.

We then wanted to understand whether our respondents felt that they were receiving adequate support and information to meet their needs and to enable them to have a healthy life balance.

Question 3: As a carer, do you feel that you receive enough support to balance your caring responsibilities with work/education and to have a life outside of your caring role?



As the chart shows, just over half (55%) of the carers we spoke to felt that the support they received was adequate. However a very high number (36%) did not feel the same way. A potential lack of support for carers may have wider implications for health and social care in the borough, because a lack of support for carers could cause further problems over time for the cared for person, for example, if their carer struggles to provide adequate care. Lack of support may also cause problems for the health and wellbeing of the carer themselves. Any future strategy and developments in services will surely need to better address the needs of carers.

One of the carers we spoke to at the Wandsworth Carer's Centre felt that the information for supporting their relative was good but that it was difficult to access information on support for carers themselves. Another carer commented on how information about privately provided respite services was difficult to obtain.

We then went on to ask if there were ways they had been supported that had been helpful, to gather evidence of good practice and how services might already be supporting carers' needs. We also asked for their views on what support they would like to see in future.

Question 4: Are there specific ways of supporting carers to have a life outside of their caring role that you have found helpful, or would find helpful?

- Take them on holidays
- Holidays for carers
- Not been able to use at the moment
- I believe the Emotional Freedom Technique is a fantastic modality to help carers on an on-going basis.
- Carers' Coffee Club to make friends
- More respite
- Going out, planned events

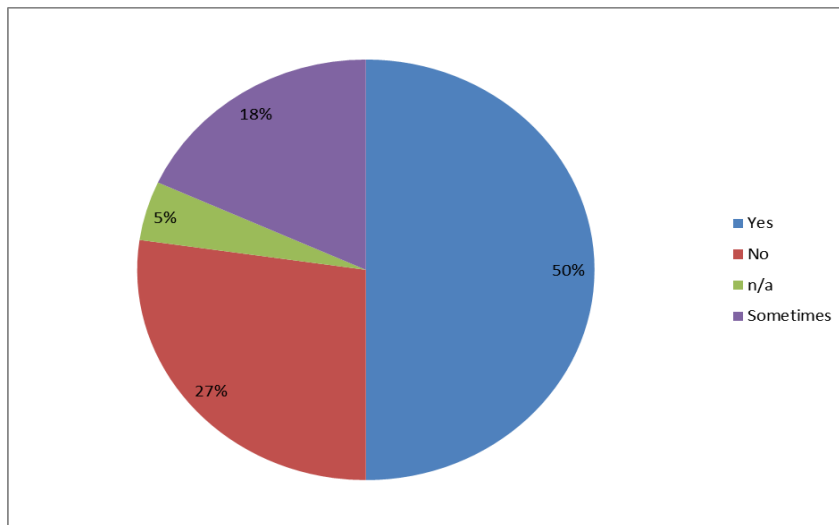
The responses above show that the support most valued by carers was respite and the opportunity for a break. Responses about holidays, coffee clubs and events suggest that opportunities for leisure time helped carers to feel like their lives had a better balance, in a situation where work and caring can take up the majority of their lives. Activities may also provide welcome company away from their responsibilities.

When we spoke to the group of carers at the Wandsworth Carer's Centre, they mentioned how important **Hospital Passports** were for the care and support of their relative or friend whilst they are away. Many commented on how important it is for healthcare professionals to recognise them as carers and to accommodate their specific needs. They also identified specific support services they have attended that helps them as carers, such as the Wandsworth Carer's Centre and family therapy. Some commented however, that as family members and carers they had had issues with a lack of engagement and understanding from professional staff.

It is important for carers to be involved in the decisions being made about the care of the person they look after, as they are often the people who best know the needs of the individual being cared for and can ensure that services provide the appropriate care to meet these needs. For the wellbeing of the carers, and to ensure that the appropriate levels of care are given, it is important that carers feel they have a measure of control over the decisions being made, and that their input and views are valued and taken into account.

We asked carers if they felt they had the right level of involvement in the decisions made about the individual they care for and whether they felt valued.

Question 5: Do you generally feel valued and involved in the decisions being made about the care and support of the person you look after?



As the chart shows, half of the respondents felt valued and involved in the decisions made. A significant number (27%) felt that they were not, and an additional 18% felt that this was only the case sometimes. This suggests that health and care services may need to explore how they can involve carers more and give them a greater sense of recognition of their hard work. This will improve the suitability of care arrangements and ensure the care is appropriate.

Next, we wanted our respondents to explore how services could value and involve them more, in order to provide some useful ideas on how to address the problem identified above.

Question 6: Are there specific ways of valuing and involving carers as partners that you have found helpful, or would find helpful in the future?

- More meetings
- Support groups, dementia cafes
- Health professional
- Social services advice / doctor
- Carers' Centre, GP, Social services

The above list shows some of the suggestions made, varying from self-help and group oriented methods, to more formal support from health and social care services.

Some of the carers we spoke to at the Wandsworth Carer's Centre said it was important to feel valued, listened to and to have their opinions taken onboard. This included feeling that they were listened to when speaking to specific health or social care services and being involved in committees, other influencing bodies and advocacy services that represent carer concerns. Having their role as carer considered as integral to the wider care package of the person they care for was important to many. One carer mentioned that it was important to include their needs as a carer, specifically their need for a holiday, in their relative's care plan. It was clear from their answers that whilst some services already work in partnership with carers, more could still be done to involve carers in the network of care and support for the individual they care for.

Our final question to carers focused on capturing further views on how carers could best be supported whilst they cared for a relative or friend. This question would also highlight the types of support that carers found particularly valuable, and that would be important to have in future to meet the needs that matter most to carers.

Question 7: Please tell us about any experiences or other forms of support that have not already been covered, that you have found helpful, or would find helpful.

- Wandsworth Carers Centre
- Meditation Selfhelp group
- We have had holidays from family fund which have found very helpful
- EFT will help carers
- Day & night service
- New to system so going + night system
- All support, carers centre

The above results illustrate the variety of support that carers need. The suggestions and responses from our group of carers suggested that support was needed throughout the day within the community and from a variety of services. Useful support includes tools like training and information. Some also highlighted that the person they care for had individual and specific needs that needed to be accommodated, with some mentioning the importance of mental health considerations, for example.

This variety in the carers' support needs reflects how caring can affect so much of a person's life and can really put a strain on their ability to cope with their own lives whilst providing care to another person. Respite, support and practical services are all needed, with a clear focus on the variety and individual nature of the needs and wellbeing of each carer. In fact in many cases it may be that there is a whole network of carers and supporters, such as wider family members and friends, who share the caring responsibility. One respondent highlighted that having the whole family trained or informed about the condition and needs of the person they care for could 'activate' them to support the individual using each of their strengths.

Conclusions

We spoke to a range of carers across a variety of groups and backgrounds. When questioned about the current services and support available for carers, we found that a significant number were either not aware of available support services or were not using the services. This is worrying, as carers, on an individual level, may not be getting the support they need. This potentially also indicates issues around a lack of involvement and empowerment in choosing the appropriate care to meet the needs of the person they are caring for and for themselves. Services may not be supporting enough carers to care for their family members or friends, nor helping them to cope with their caring responsibilities, which could lead to further health and wellbeing problems for both the cared for person and the carer.

Our respondents reflected the variety of circumstances that carers may find themselves in. It was important to the respondents that they have access to respite and shared leisure activities with others, but also more formal support from health and social care services to enable them to deliver care and to take care of their own health and wellbeing. Therefore, support and services for carers needs to encompass various aspects, from grants and funding for independent respite, to organised social activities, but it also needs to provide practical tools like training and easy access to health and social care professionals and professional advice.

Finally, responses to our survey highlighted the significant responsibility carers feel towards the health and wellbeing of the person they care for. One carer highlighted that “When things go wrong, we as carers feel responsible”. With this role and responsibility comes demands on the carer for which they need to be supported and trained. Each carer has a unique set of strengths and insights into the needs of the person they care for. Services providing care and treatment need to recognise and address the unique needs of carers, in order to help them cope with managing their caring role and the many other aspects of their lives.

Many of the carers we spoke to suggested that they should be considered as an integral part of the network of support for their relative or friend; being involved in the communications, planning and decisions, where appropriate. One respondent highlighted that “We want to be partners in care. We want our expertise and strengths recognised in the care of our relatives” and that “Carers have strengths as well as needs”. Identification of carers and accommodating their needs within the network of care is important, as is raising awareness amongst carers of the support and services available to them.

Appendix A

The Questionnaire

The Department of Health are **developing a new strategy for carers** which reflects their lives, aims to address any health or financial concerns they may have, and provide services that support carers to live well, whilst caring for a family member or friend.

This survey is an opportunity for carers, those who have someone care for them, businesses, social workers, NHS staff and other professionals that support carers, to share with us their views on how more can be done to improve support for carers.

Are you a...? (*tick all that apply*):

Paid Carer Unpaid Carer Young Carer Other

Please comment: _____

Have you received information and advice on the support services that are available for carers?

Yes No **If yes, what services or support *have* you found helpful or *would* you find helpful?**

Please comment: _____

As a carer, do you feel that you receive enough support to balance your caring responsibilities with work/education and to have a life outside of your caring role?

Yes No

Please comment: _____

Are there specific ways of supporting carers to have a life outside of their caring role that you have found helpful, or would find helpful?

Please comment: _____

Do you generally feel valued and involved in the decisions being made about the care and support of the person you look after?

Yes No

Please comment: _____

Are there specific ways of valuing and involving carers as partners that you have found helpful, or would find helpful in the future?

Please comment:

Please tell us about any experiences or other forms of support that have not already been covered that you have found helpful, or would find helpful

Please comment: _____

Appendix B

Consultation on the new Carer's Strategy

Answers from 6 carers.

Note: the term 'relative' is used in this context to mean the 'cared for'.

What information, services or support would you find helpful to support you as a carer?

- Emotional support
- To know that my relative is getting the best possible service. This gives me peace of mind.
- Receiving the correct information. You often have to find the information yourself.
- Advocacy for carers – in regards to getting my point across to support workers or health professionals who look after my relative. For example, one carer found it difficult to get their point across to the Community Mental Health Team (CMHT), regarding decisions for their relative's care. It was only when the Carer's Centre spoke to them on the carer's behalf that they listened.
- For professional staff to look at/take into account the needs of the carer/s and families.
- Support to adapt to the role of caring for a relative, and have this support tailored to each individual carer.
- Equip carers with the tools they need to care for their relatives.
- It is important for carers to identify themselves as carers.
- In situations where there are multiple carers for a relative, each carer should have support. Each family member or relative involved should be considered, with regards to their strengths, their needs and the effect it will have on them. For example, in the case of a family where a son is going through clinical depression, the whole family should be given information about his condition and what he is likely to be going through. This informs the family, and could activate them to support him using each of their strengths.
- Health professionals need to have good communication with carers, before implementing a plan of action.
- **Prevention** (before a potential crisis/relapse in the relative's condition) – via support, education and awareness of a relative's condition which could positively affect the way their family interacts with or cares for them.
- Awareness of roles. For example, who is responsible for meeting each of the needs of the relative?
- Up-to-date information and carer's training on administering medication. I was previously able to administer medication to my relative, but now, because of the NICE guidelines, I am not able to.

What would help you to feel valued as a carer?

- Being listened to as a carer
- Giving me feedback on my carer's assessment

- Being able to go on holiday once a year. For example, by integrating into the relative's care plan the needs of their carer/s to go on holiday once a year.
- To be asked for my opinion and input into the care plan of my relative, and for my opinions to actually be taken into account. For me to be involved in the finalisation/final draft of the care plan.
- Having a multidisciplinary team – joined up working

What services or support have you found helpful?

Examples of where support for carers is working.

- The team at the **Gunning Ward** at St. George's Hospital involved me in the care/treatment of my relative.
- Being a representative on committees – for example, the Acute Mental Health Forum, Wandsworth Self-Management Forum, BME Mental Health Forum and the IAPT Steering Group.
- Hospital Passports are crucial. When a carer isn't around to support their relative, the passport enlightens the team that is caring for them.
- The Primary Care community matron and doctor came to my house to do a community assessment. This provided relief to me. They let me know what they were going to do next.
- Carers and service users being involved in the Enhanced Primary Care for Mental Health, which will be starting in October 2016
- Professional staff adapting their care for a relative, around the needs of that relative. For example, professionals caring for an asthmatic patient took into account her mental condition/illness and adapted their care of her around this.
- The learning disability team liaison nurses at Clare House, at St. George's were wonderful. *Support for carers is quite patchy within mental health, so we need to bring everything up to the level of the best examples of good practice.*
- Having myself identified as a carer. My GP put it on my file that I was a carer, so when I go for an appointment, the doctor knows I'm a carer (and may need a longer appointment).
- Occupational therapists are absolutely wonderful at being inclusive of carers. They use the social model approach. They are grounded in the day-to-day issues that are carers' concerns.
- Wandsworth is really good in the amount of funding they put into mental health.
- There is an amazing Doctor who sits on a strategy group I attend. He is always looking at ways an issue can be solved. He takes carers' issues forward. Clone him!
- Wandsworth Carer's centre
- The way they work at the forensic ward at Springfield Hospital is different. They offer family therapy, carers are involved, carers are asked how they are feeling and are invited to CPA's.

Are there specific ways of supporting or involving carers that you would find helpful in the future?

What could be done to improve?

- Information at the GP – for example, information can be displayed on the LED screen, the TV, or in the magazine section.
- Tapping into the expertise, knowledge and strengths of carers and involving them in every aspect of their relative's care. Recognising that families and carers are a resource and **investing** in it. Carers are saving the government a lot of money.

- Improved funding in mental health. This can have a positive knock-on effect on the quality of services.
- Recognising each family as individual – that not every family will want a direct payment, and it may not be suitable for each family. Sometimes direct payments can be a complicated process, adding paperwork, additional burdens and stress in addition to caring for a relative.
- Not pressurising people to receive personal budgets as a direct payment.
- Training professionals and staff to be more aware of families and carers.
- Don't lump all carers together (in your definition and perception of them). Each carer has a different set of responsibilities, needs and wants. They have a range of expertise.
- Training for families and carers.
- I would like to see closer working and awareness from statutory services of the work that the voluntary sector does and the value of the voluntary sector.
- Identification of carers and signposting them to support services. It's ok once they get into the system/support service, but what happens before this?
- Recognise the complexity of the social connections of the relative being cared for, and the concept of 21st century families.
- Recognise that not all carers just want money.
- Support for older carers who may have a mental health illness or dementia.

Comments

- Information around support for the relative being cared for is really good, but information about support for carers is difficult to access.
- If someone would like to take on the responsibility of arranging respite for themselves, it is difficult to get information about privately provided respite. Some carers may want to take on the responsibility of finding and paying for respite themselves, but may be told to contact social services. However, they may not want to go through social services.
- Professional staff aren't particularly good at looking at the needs of families and carers.
- Professional staff and their engagement with families & carers has been an ongoing issue. A solution to this could be training for the professionals to engage with families & carers.
- I believe there should be an overall strategy, all through the pathway, from when a person identifies as a carer, right to the end. Even ex-carers need support.

Some quotes within the report

- *"Carers have strengths as well as needs. We want to be partners in care. We want our expertise and strengths recognised in the care of our relatives."*
- *"Mental Health is much nicer than it used to be, but funding is where the government is going wrong".*
- *"When things go wrong, we as carers feel responsible".*