

# **Working Together with Carers for the Isle of Wight 2013 to 2016**

**The Isle of Wight's consultation report**

**Developing an Isle of Wight  
carers strategy to meet local needs**

Report written by  
**Yvonne Millmore**  
commissioning officer  
Isle of Wight Council

## Acknowledgements

Thank you to everyone who took part in the consultation by either completing the carers' survey or attending a consultation event. We would also like to thank Carers UK for their continued support.

## Executive summary

The Isle of Wight Council and the Isle of Wight Clinical Commissioning Group are working to improve the lives of carers and give them the opportunity to be consulted about services and decisions which affect them. We believe that involving carers in these processes will lead to better decision making by service providers and commissioners. We want, in line with government policy, to provide people with genuine control and choice over how they are supported.

There are approximately 16,500 carers providing some level of support to family, friends or loved ones on the Island.

The *Working Together with Carers 2013 to 2016* consultation was commissioned by the Isle of Wight Council and the Isle of Wight Clinical Commissioning Group to obtain carers' views on the carers' plan and their experiences of services for carers. This consultation has provided valuable insight into what is working well, and what is not working so well. Carers and their families have identified how the Island can improve its support and facilities and support for carers of all ages.

Following publication of this report it is intended that an action plan will be drawn up by the carers sub-group, a group made up almost entirely of carers organised by *People Matter* - the Island's user-led organisation. The plan will identify priorities and monitor our progress in providing continuous improvements in line with the strategy.

## Definition of a carer

There is no single definition of a carer. The law makes reference to carers in many contexts.

In general, carers are usually family members, friends or neighbours who provide physical care, emotional support, advice or advocacy support to another person and are not paid for providing that care (nor is he or she providing the care as a volunteer placed into the caring role by a voluntary organisation).

## Consultation approach

The consultation was launched on 3 January 2013 and closed on 25 February 2013. In order to engage widely with carers, 16 different events were held across the Island – in local supermarkets, Ryde Superbowl, libraries, St Mary's Hospital and at various carers' groups at different times of the day in order to fit in with the needs of carers. People were able to discuss individual issues, obtain information on carers support and services available on the Isle of Wight.

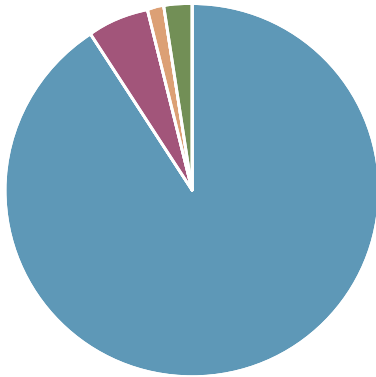
- At these events people were encouraged to submit formal responses by completing a carers' survey which could either be filled in at the event, taken away to complete later or done online.
- Consideration of how to engage with carers was supported by the local branch of Carers UK which sent out survey information to 600 carers registered on their mailing list.
- GP practices were sent an e-shot of consultation events, with copies of the *Working Together with Carers 2013 to 2016* plan along with printed copies of the carers' survey.
- An advertisement was placed in the Isle of Wight County Press advising people of the carers' survey and the local networking events across the Island.
- A GP survey consisting of five questions regarding the *Working Together with Carers 2013 to 2016* plan was sent to all GP practices across the Island.

Amongst the feedback received from this survey one practice commented:

“Carers of all ages need to be recognised and supported in their role, more needs to be done to identify who they are and the valuable and loyal service they give. We need to help carers realise what a big part they play in looking after their loved ones, relatives, friends and or neighbours. Often the care given can lead to monetary hardship and these proud carers will not ask for support or help because they think it is their duty to care. It is our duty to care and support them through community, council and the NHS.”

After the closing date (25 February 2013) all surveys were collated and analysed by the commissioning officer for carers.

### Are you a carer?



- Yes, currently (91%)
- Not currently, but have been previously (5%)
- Not currently, but maybe in the future (1%)
- No (3%)
- Don't know (0%)

It is clear from the survey that the Island has a high number of carers. Most carers are aged over 25. No young carers or young adult carers completed this survey, although 4.3 per cent of respondents highlighted that they had been young carers in the past and the overall majority felt that a separate strategy for carers aged up to 18 should be written.

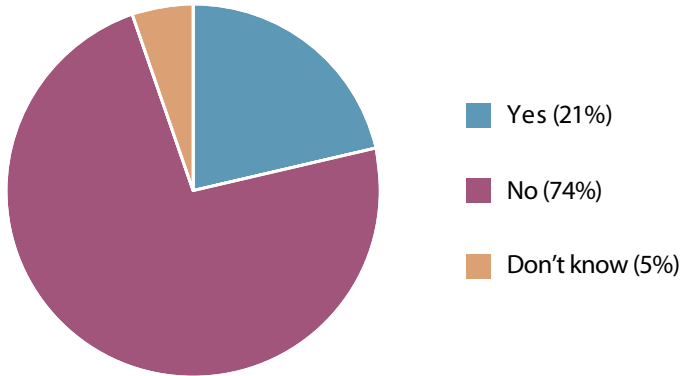
There has been a 14 per cent increase in the number of people identifying themselves as carers on the Isle of Wight between the 2001 and 2011 census, with a 43 per cent increase in the number of people who identified that they were caring for someone between 20 to 49 hours each week and a 25 per cent increase in the number of people caring over 50 hours each week.

We know that many carers do not identify themselves as carers but see their role as a natural extension of family obligation and we hope that by raising awareness of carers services and support that we will reach out to these carers.

### **Survey responses from carers on the Isle of Wight**

Visits to local carers' groups led us to believe that the current Isle of Wight Carers' Strategy 2009 to 2012, along with commissioned services for carers support and who to contact in a crisis, were not well known. The survey confirmed our concerns and the results are clearly identified in the following graphs.

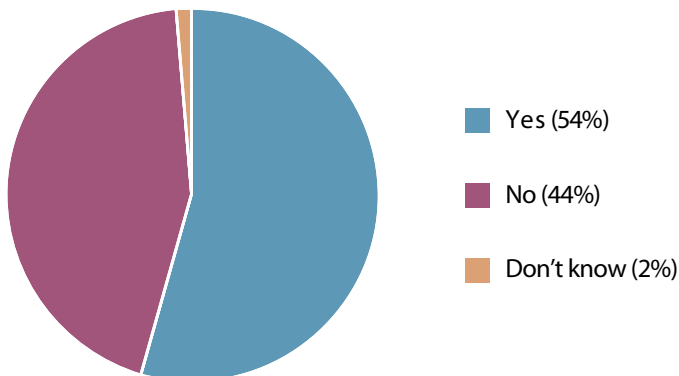
## Were you aware of the IW Carers' Strategy?



We have included some comments captured from carers completing the survey:

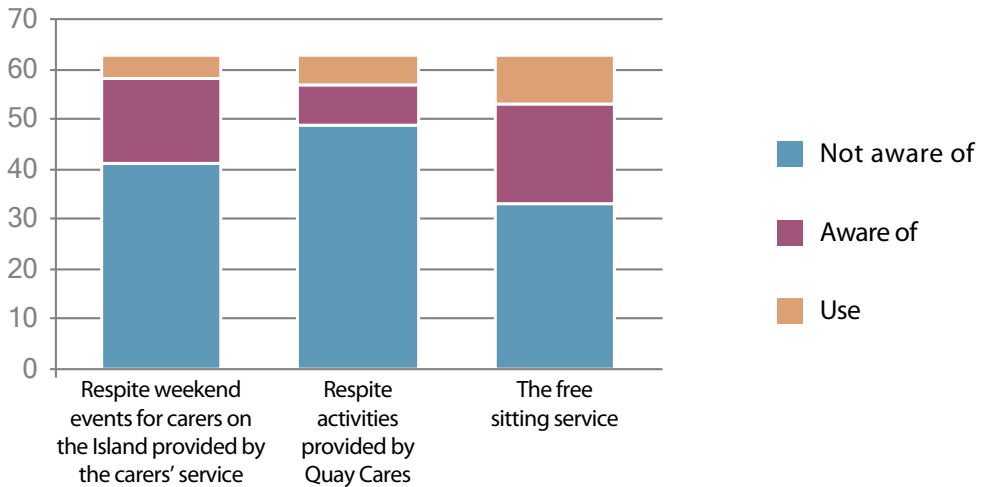
“Information from social services is often different and conflicting.”

## Have you ever tried to find out about carers' services that are available to support you?



“Did not know who to contact. No advertisements for carers in need.”

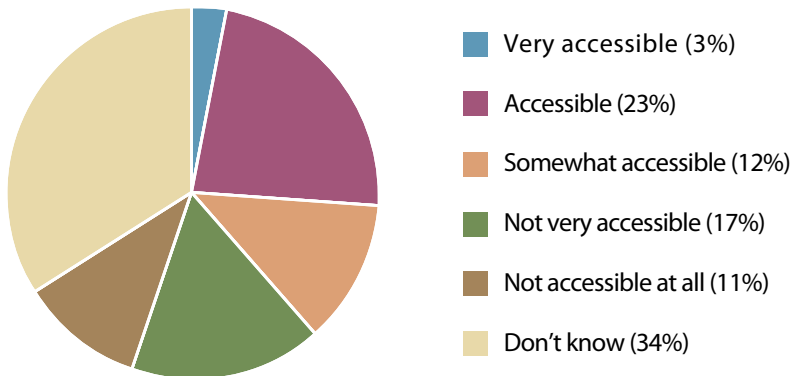
## Which of the following services do you use or are aware of?



“It has taken six to seven years to become aware of all that goes on for carers, through initially attending a carers with confidence course, then eventually receiving Carers UK news letter.”

## How accessible, if at all, are the current carers' services for you to contact?

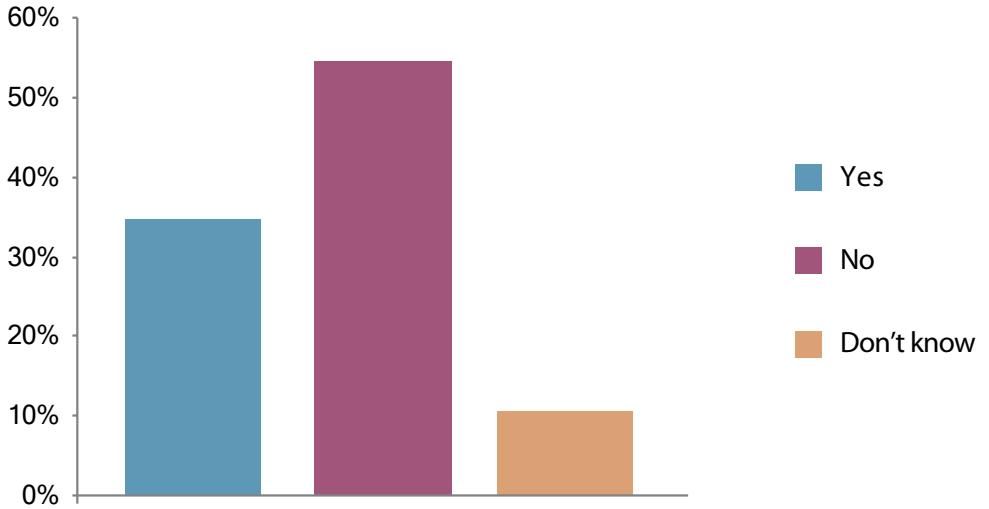
From the current services available to carers we asked how accessible these services are and gained the following responses:



“Not aware that there were any carers' services in our area.”

The overall response to when carers would like services available to them was Monday through to Sunday, 9am to 5pm with an emergency number for times of crisis outside of these hours.

## Do you know who to contact in a crisis?



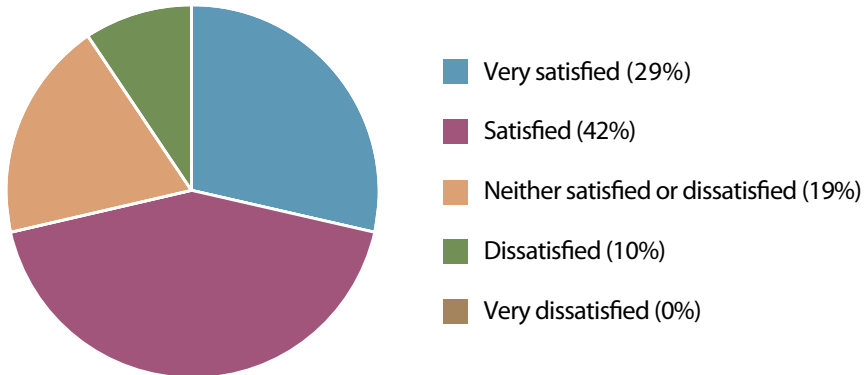
“Need a crisis number - someone to call if the situation won't wait till working hours?”



## How satisfied or dissatisfied are you that the carers' group meets your expectations?

We wanted to know how many carers attend carers' groups and if there was any need for change or improve these.

- 30.7 per cent of carers advised us that they attended a carers group.
- 69.3 per cent of carers do not.



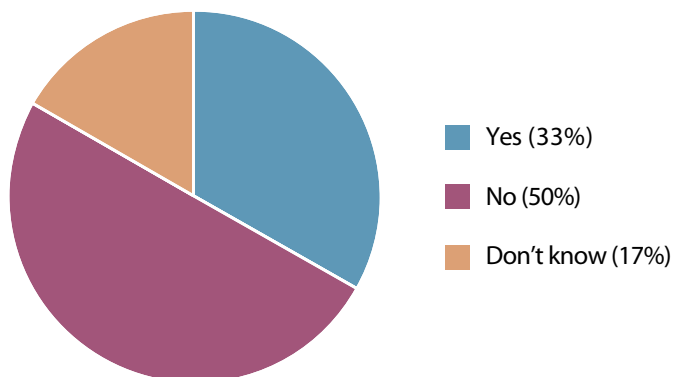
When we asked if carers' groups needed to be changed or improved, the following comments were received:

“A clearer picture of which organisation is active in which field. There is unnecessary duplication.”

“The needs of carers are very diverse; often it depends on who you care for. Caring for those who need different provision should be recognised.”

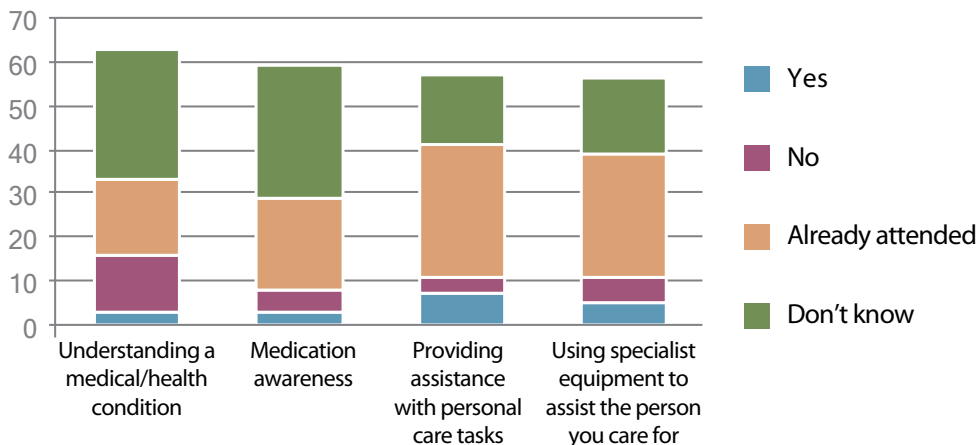
## Do you have the opportunity to access a support group for people of your own age?

The survey identified that 50 per cent of carers do not have the opportunity to attend a carers group for people their own age:



## Would any of the following training courses help you in your caring role?

In order to support carers in their role of caring we asked if certain training would be of interest to them and received the following responses:



We also wanted to identify if carers have received a carers assessment and how they felt this experience was for them.

68 per cent of respondents said that they have not received a carer's assessment, the response from those that had felt the carers' assessment process is poor.

*"This was done in such a way that I didn't know until much later it had been an assessment of my needs."*

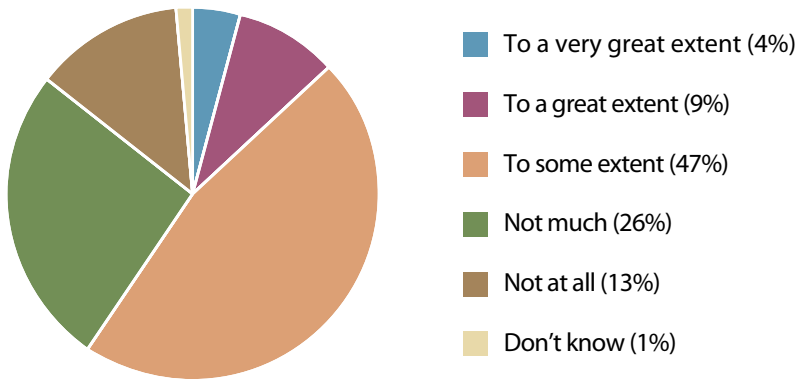
*"Information needs to be given to carers, assessments should be done. The focus is normally on the needs of the person who is cared for not the person who does the caring."*

## To what extent, if at all, are you able to maintain an acceptable balance between your caring responsibilities and life outside caring?

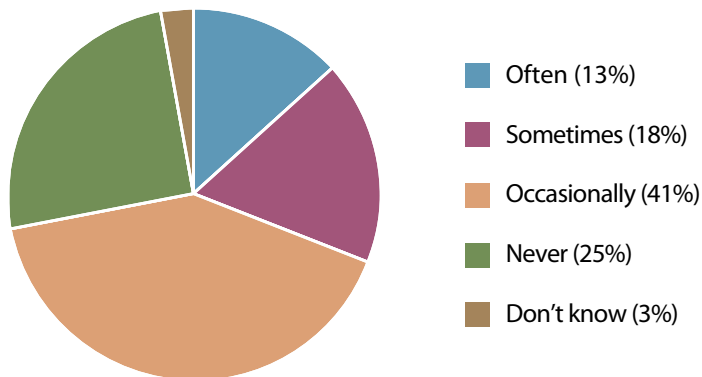
In order to look at the future for carers and services available to them we asked carers how their caring role impacted on their general life. Were they able to maintain an acceptable balance between caring responsibilities and a life outside caring? How often, if at all, were they able to take a respite break from their caring role?

89 per cent of respondents recorded that their caring role impacted on their general life.

Only 13 per cent of carers are able to maintain an acceptable balance between their caring responsibilities and a life outside of caring.



## How often, if at all, are you able to take a respite break away from your caring role?



25 per cent were unable take a respite break from their caring role.

62 per cent of respondents identified that looking after someone had affected their own health, with 24 per cent of carers needing to cancel their appointments with their doctor due to not having anyone available to support the person they are caring for.

66 per cent of carers that responded to our survey said that their GP was aware that they were a carer, although 81 per cent of carers identified that they have never been offered an annual health check by their GP.

13 per cent of carers were aware of carers information within their GP surgeries.

“I was very pleased to see that there is a large notice board in the St Helens surgery devoted to carers. There is loads of info on the board.”

We recognise that caring for someone can be a full time job, we are also aware that 32 per cent of carers who responded to our survey are employed,

66 per cent working full time hours and 24 per cent working part time.

13 per cent of carers responding have changed the times they work in order to continue providing their caring role, with five per cent reducing their hours to part time.

48 per cent of responders to the survey have given up employment due to their caring responsibilities.

“I have gradually reduced the hours worked, my colleagues have been extremely flexible and supportive in how I have tried to maintain work and caring role until this year. I have now resigned from my job. I would like to work part time but at present do not know if this is possible.”

The analysis of the responses drew out several themes and similar views with respect to what were the most important things were for carers and what is working well and what needs to be improved for carers on the Isle of Wight.

## What's important?

- Support and help, especially in time of a crisis
- The support of family and friends
- Maintaining that the person being cared for is safe and well
- Training and advice
- A good care plan and a supportive care manager
- Information and signposting
- Respite and time for the carer
- Assistance with finance and benefits
- Travel costs

“Availability of information in one place. It tends to be by chance that you find out much of what might be available. Most information directed at us has been centred around the child, not around the carers.”

## What is working well?

- Memory clubs and mental health services
- Alzheimer's Café
- Alzheimer's Society Carers Group
- Free sitting service
- Quay Carers
- Carers UK and Carers Groups
- Other voluntary groups
- Johns Club
- Respite/day care
- Well supported personal budgets
- Support of friends

## What needs to be improved?

- Consistent and accurate information and signposting
- More activities and support for both the cared for and the carer
- Funding for carers groups
- Crisis support 24/7
- Promoting awareness of different carers, carers of older people, young carers caring for parent/s other siblings, parent carers, etc.

“Short notice sitting service – probably impossibility! Having to plan outings over a week ahead to book sitter does not allow for weather changes or spontaneously.”

## Conclusion

Summary of key messages of what to improve for carers on the Isle of Wight:

We want to focus on the things that mean the most to carers and make the biggest difference – we are confident that in delivering these things, we will move towards achieving better experiences and better lives for carers.

Generally, all carers that we met agreed the need for comprehensive and consistent jargon free information about services in their areas. This should include information about the benefits they may be entitled to, carers groups and respite care.

Carers report that they spend a great deal of their energy and time trying to understand what services are available and who is responsible for doing what.

Carers feel that it is extremely important to know where to go for support and have access to a central point both during office hours and an out of hours crisis contact. It was felt that this central point should be able to signpost for support with regards to benefits, housing, employment, therapeutic interventions, and assistance with recruiting for personal assistants.

Support for former carer support is necessary in order to provide counselling and signposting to other network groups and activities.

There is a need to look at carers groups' and respite activities to give everyone the opportunity to attend a group which interests them and fits within their age group.

Male carers in particular would like to join groups with other male carers.

There was generally an agreement from all carers that there needs to be an improvement in the carers assessment process and the need for personal budgets for carers to enable greater flexibility with carer respite opportunities.

There needs to be earlier recognition and signposting for support for carers through GP surgeries.

## References

- *Carers and Their Rights – The Law Relating to Carers* by Luke Clements  
Fifth edition 2012
- Census 2001/2011