

DRAFT Report on the carers questionnaires (September 2016)

Background

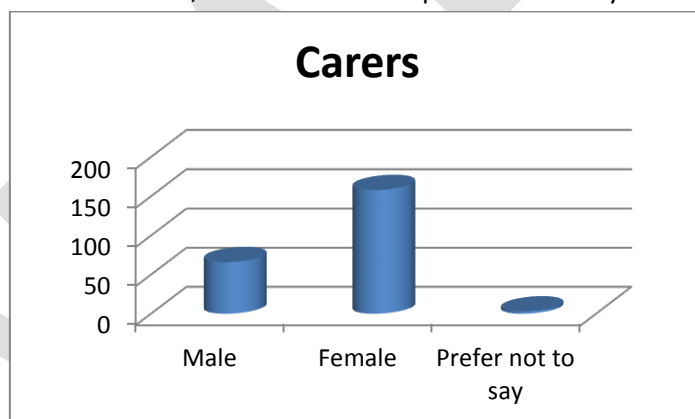
As part of the consultation process around the Population Needs Assessment for Gwynedd, over a thousand questionnaires were sent to Gwynedd carers registered with either Carers Outreach Service or Hafal. 227 questionnaires were received back.

The consultation questions were based on the requirements of the Assessment and also the Social Service and Wellbeing Act (Wales) 2014. The following were asked:

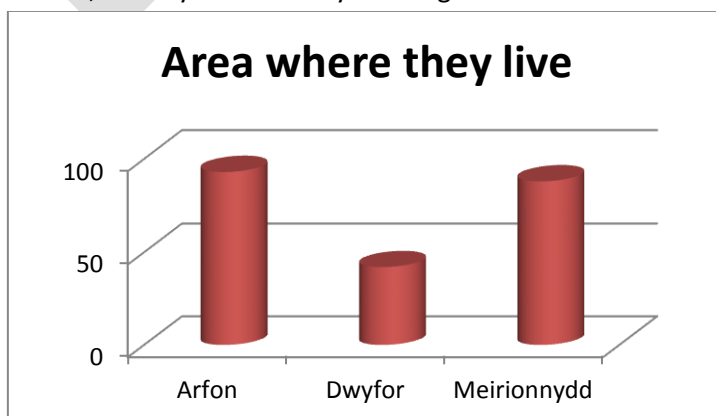
- What are the challenges you face in your day to day life as a carer?
- What or who supports you to overcome these daily challenges?
- How do they support you to overcome these challenges?
- How well is this support working for you?
- How can the support be improved?
- How do / could your friends and family help?
- How do / could your local community help?

Profile of the carers who answered

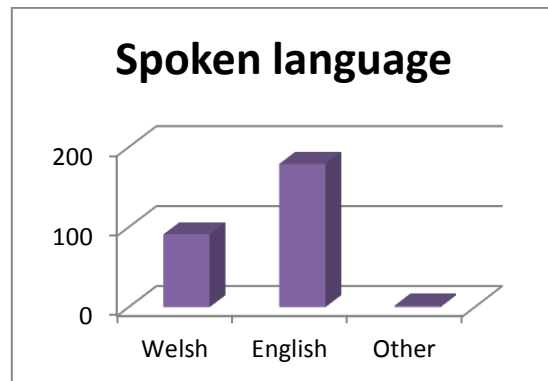
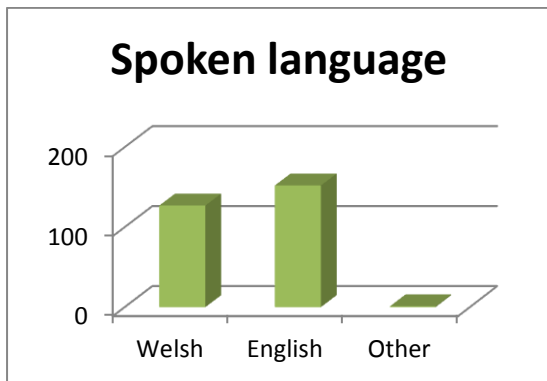
Almost 70% of the carers are female, 29% male and 1% prefer not to say.



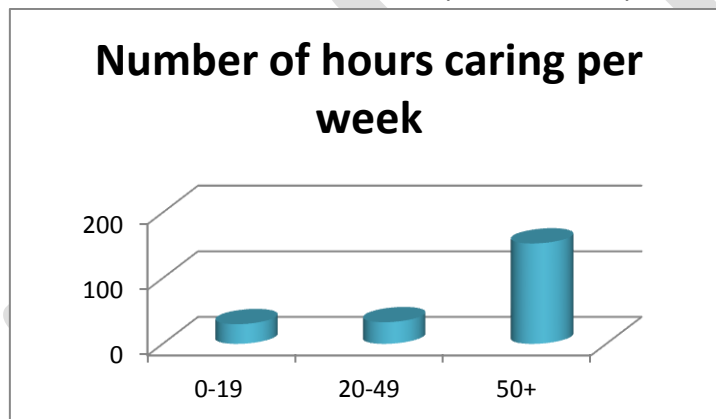
Most live in Arfon and Meirionnydd (41% from Arfon and 39% from Meirionnydd), only 20% of the carers live in Dwyfor. It is hard to know whether the response from Dwyfor reflects the number of carers there i.e. that there are less carers in that area compared with the other two areas, or because of historic reasons, namely the difficulty working with carers in the area.



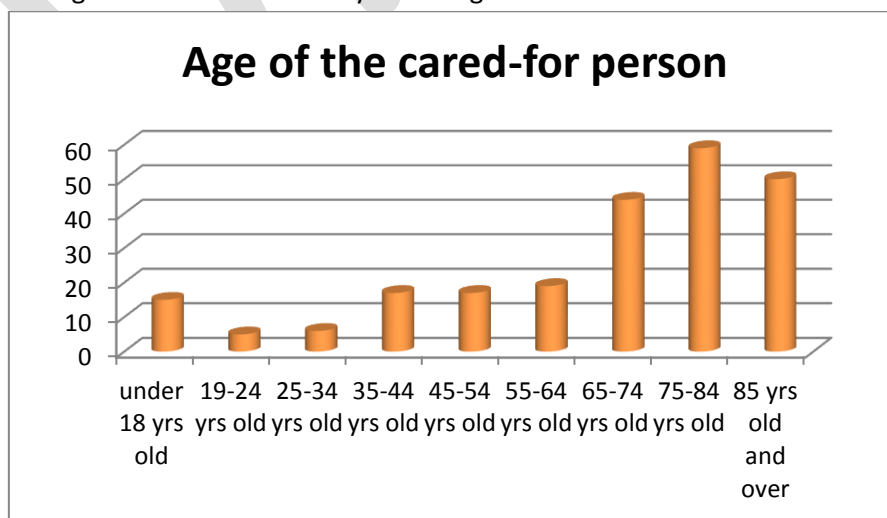
From the point of view of language, most write in English (79%) but although English is the language spoken by the largest number, carers who only speak English are in the minority because a number of carers noted they speak both languages. This underlines the importance of providing support services in Welsh to Gwynedd carers.



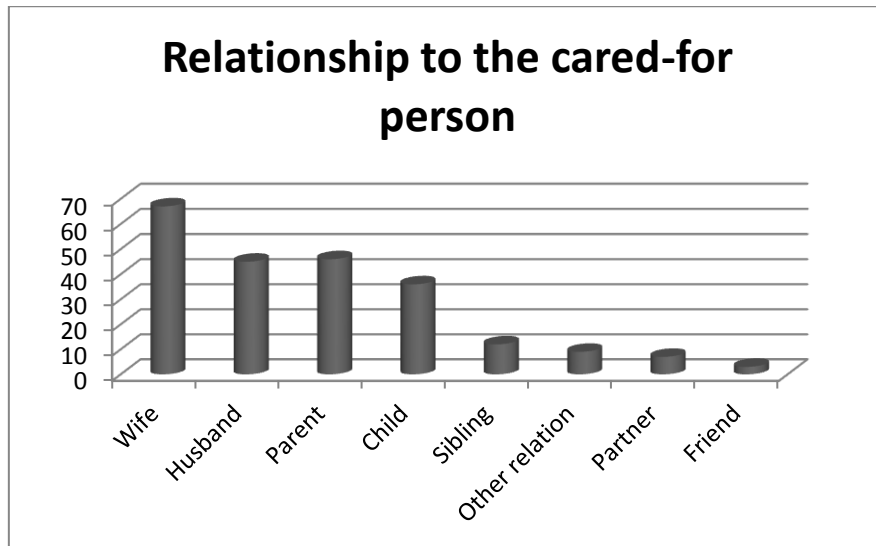
67% of the carers care for 50 hours or more every week, with 15% caring between 20 - 49 hours a week and 13% up to 19 hours. The other 5% of carers say the hours vary from week to week.



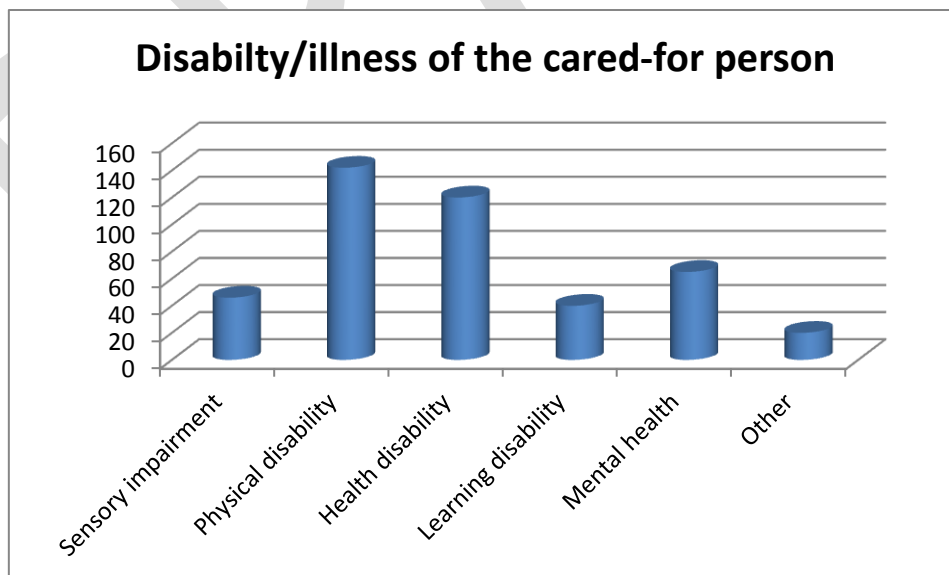
Most of the people who are cared for are over 65 years old (66%) with 45% of them over 75 years old. The smallest group of people who are cared for are those between 19 - 34 years old. 15 carers are parents looking after a child under 18 years of age.



From the point of view of relationship to the cared for, the majority are wives but there is less of a difference between the number of wives who care and the number of husbands than there is between the number of mothers and number of fathers. Out of all the parents who care, over 90% are mothers, and it is the same pattern with children who care for their parents, and brothers and sisters for a sibling; 72% daughters and 75% sisters.

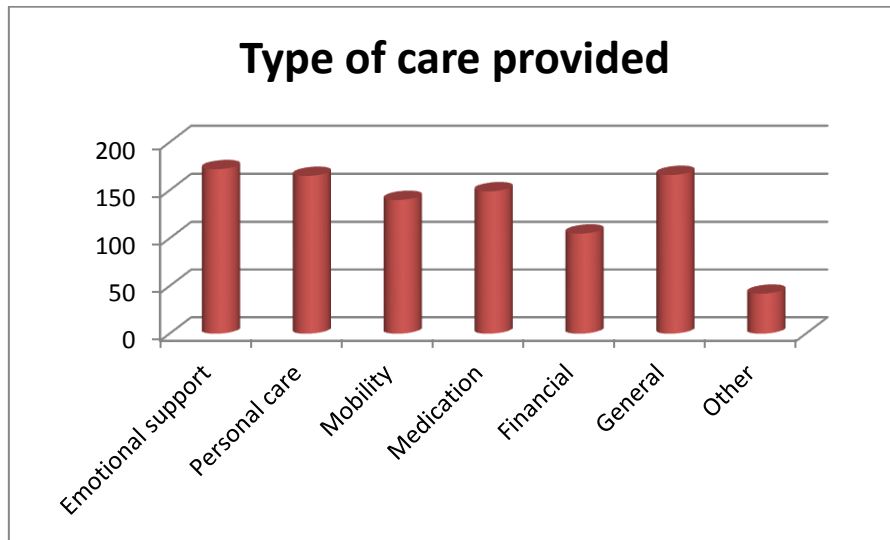


A lot of the carers are looking after someone with more than one illness or disability. Although some note only one disability, the majority note more than one, with many noting up to four. The complicated health condition of many of the cared-for is reflected in the number of hours the carers are caring every week.



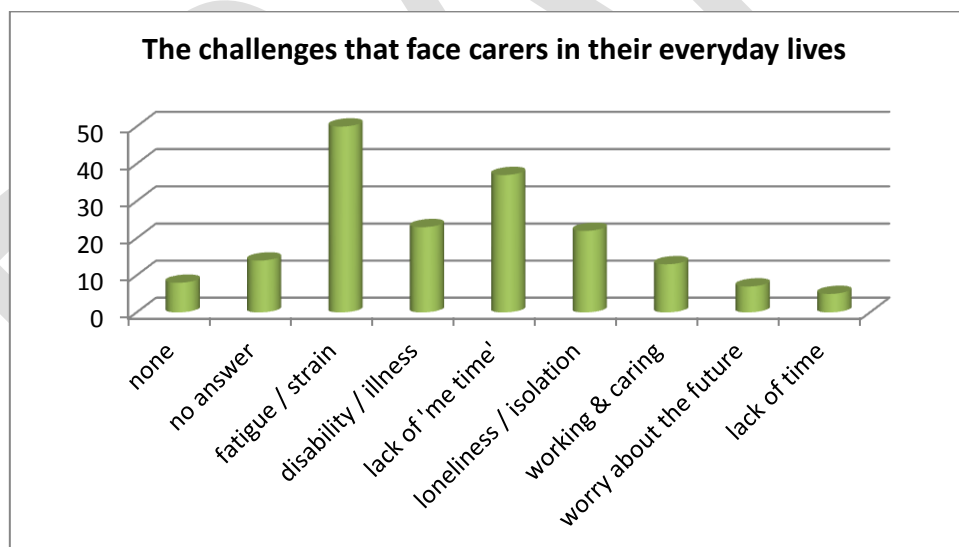
Very few note that they provide only one sort of care; a lot more say that they do everything. Some of the men note housework and cooking as part of their caring role and it must be recognised that

coping with these tasks which they had not done before can be a real challenge for an elderly man trying to complete them on top of everything else he is doing whilst caring for his wife.



The challenges that the carers face in their everyday lives as carers

Carers were asked what the challenges in their everyday lives as carers were and although every answer, like every situation, is different and unique, there are some themes which arise regularly as shown in the chart below.



Fatigue and/or strain is the biggest challenge (22% of the carers noted this); sometimes the problem is fatigue only - some say that they do not get a good night's sleep - and sometimes it is only strain. A lot mention emotional strain. Often carers face a number of challenges with one causing another e.g. lack of support/time for oneself is causing strain for one carer:

"Lack of understanding from other people. Lack of understanding by family members who refuse to accept difficulties. Having no time to myself, although my wife tries her best and feels a burden, which is not true. I feel I can do everything, but sometimes I break down."

A feeling of isolation or loneliness adds to emotional strain and causes a number of carers to suffer from depression. In reply to this question one man wrote: *"Loneliness & despair."*

Many of the carers have health problems themselves (over 10%) and some are seriously ill (including cancer) or they have a physical disability.

"... I have a spinal problem that I was offered a spinal fusion operation for but have put it off due to long recovery time."

In noting that 45% of those cared for are over 75 years of age and the spouse is usually the carer, it is obvious that a lot of the carers are elderly, and some note this as a cause for concern on top of their health problems, fatigue and strain.

"As a 79 yr old with arthritis. Who has to keep a strict time table with meals for my husband who has no stomach. Routine. Relentless. Day to day. Tiredness. Seeing to house maintenance. Paying bills. Worrying about money. Wishing to do admin jobs I can't get help with. I still run a clean tidy home. And home cook as far as I can...."

16% of the carers mention the lack of time for themselves, with some noting that they have to be on call 24 hours a day; that it is impossible to have a holiday and that there are not enough hours in the day.

"Being 'on-call' for my wife 24 hours a day, 7 days a week, as she is totally dependent on myself for all care tasks. The challenge is not being able to leave the house when I want. Everything has to be planned ahead."

Lack of time to relax can increase the problems of fatigue and strain for the carer and, in the end, affect their health, so the opportunity to have respite care is very important.

Although some of the carers still work, they mention this as a challenge, and some say that, as carers, they do not have support/understanding from their employers/workplace, which causes problems/extra strain for them. A few noted that they had to give up working because of their caring role which has caused them money worries.

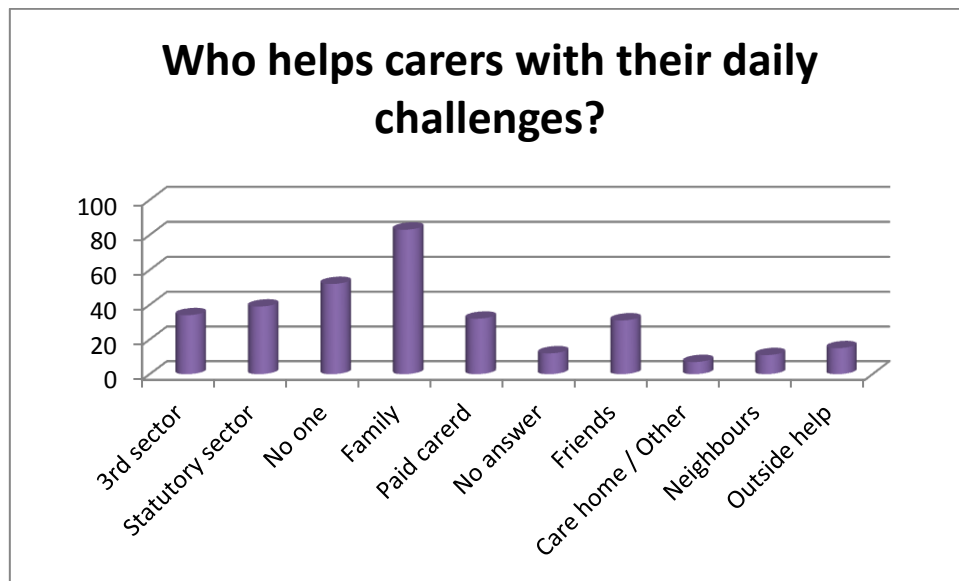
Very few say that they have no challenges, with some saying they are all right 'at the moment' and others saying they take things day by day; or as one said, *"I just get on with it!"*

Who or what helps the carers overcome the daily challenges

Family is the biggest group of people who helps these carers, but it is necessary to note that it is not only the family who supports them to overcome the daily challenges. Although 37% say that their family help, only 17% say that only the family supports them. The next largest percentage is those who say that no one helps them, namely 23% which is almost a quarter. This is a substantial number and a cause for concern, considering the nature of the challenges identified, but also raises the following question; what do people/carers consider to be help? Everyone received their questionnaire from a 3rd sector organisation that exists to support them as carers and with whom they have registered. Do some people think only of the statutory sector as providers of help and support?

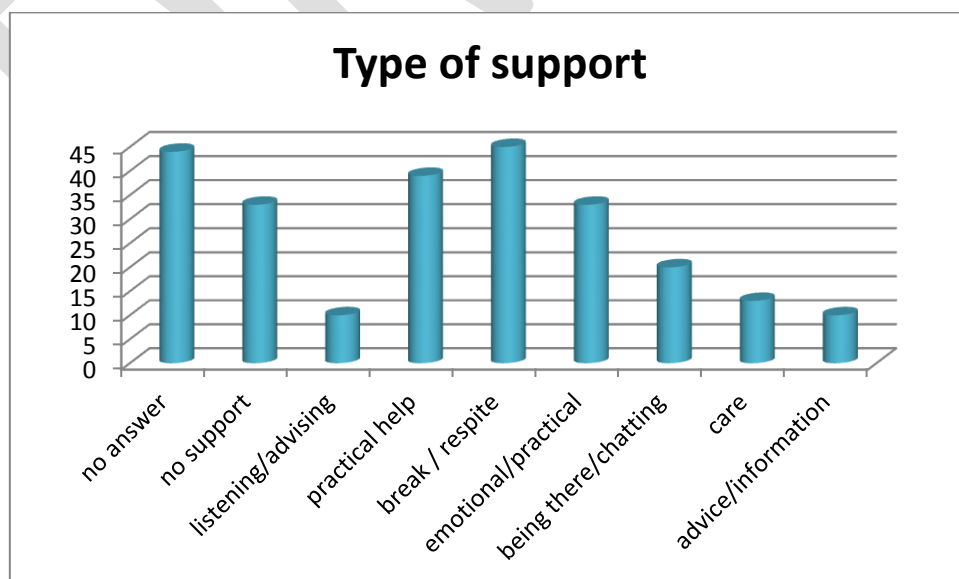
Very few consider either the statutory sector (social services or health) or a third sector organisation (Carers Outreach or Hafal) as the only people who support them. Usually, the carers get help from different sources, e.g. statutory sector, 3rd sector and family, or family, friends and 3rd sector or statutory sector. A fair number (over 10%) say that the paid carers are the people who help them.

55% of the carers note family, friends and neighbours as a source of help to them, which is exactly the same as the carers who note 3rd sector, statutory sector, paid carers, care homes and other outside help.



How they help the carers overcome the challenges

In considering the number of carers who say that nobody helps them, it is not a surprise that almost 34% failed to answer the question about the support provided or else note an absence of support.



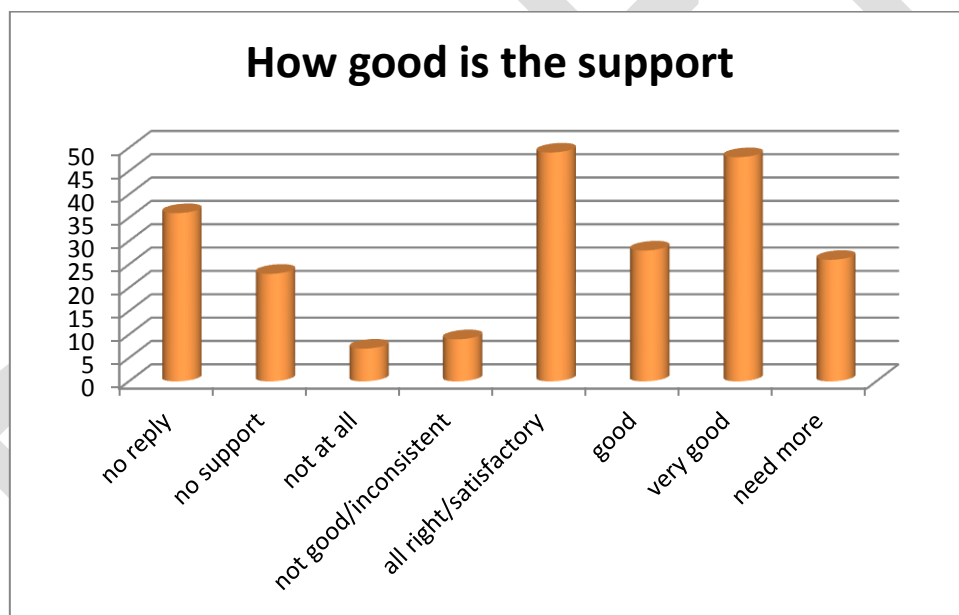
But the biggest support is the chance to have a break or respite (20%) and although a number refer to the hours of respite they get each week through the statutory sector, a number use the time when the paid workers are there to have a break: " *Talking - take time to help with chores. Also they take time for me to do other things* ".

A substantial number depend on other individuals, usually a family member but sometimes a friend or neighbour, to take over the caring role to give them respite, be it a few hours, overnight or a whole week. " *They stay over night in turns so I can sleep.*"

Again the carers usually mention more than one sort of help, and many of them receive practical help, including transport. Some note that they have emotional and/or practical support and others consider the fact that someone is there for them is sufficient; listening and chatting is important: " *Just being there to talk to & make suggestions.*"

Although we know the importance of information for carers, only a few of this group of carers mention advice and information as the sort of support they receive..

How well is this support working



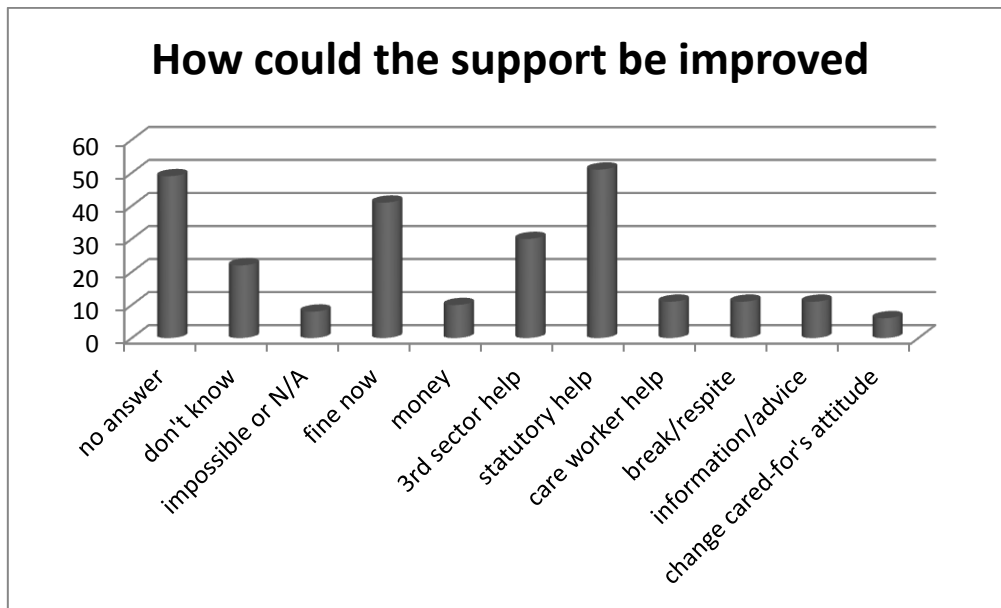
It seems that, usually, the support is working quite well, with 33% of the carers thinking that it is good or very good. However 17% note that they have no support, or the support available is not very good at all, or is inconsistent, and 22% are merely satisfied with the support they receive. Over 10% note that they need more support:

" *My son is my only support but not available for extended periods, although he intends to try to get here more often. Basically I feel on my own with this and I know it can only get worse.*"

How can the support be improved

The biggest percentage of the carers did not answer the question as to how the support could be improved or said that they did not know (31%). A few think that it is not possible to improve the support because of the circumstances; for example one carer wrote, " *No easy answer to this*

question. My wife is severely depressed and is unable to communicate easily. There is no cure to either". The cared-for's attitude can be a major barrier to the carer getting any support at all i.e. the support is available but the cared-for 's attitude prevents the carer accessing it.



On the positive side, 18% think that the support is fine and does not need improving. When mentioning how the support can be improved, many referred to the health services as well as services provided by social services. They mention a number of improvements such as more respite and care hours, out of office hours' support, better transport, people to be there to listen and to share information about what support is available.

"I am very satisfied with the level (and quality) of support that we receive and it is difficult to see how this could be improved given the limited resources available to the caring services. An additional block of 3-4 hrs of respite care (each week or fortnight) would be of great help but it is difficult to see how this would be possible under current funding."

Some answers are a reminder of the fact that a little help sometimes is what makes a difference to carers, such as *"I love to be able to go out sometimes for a few hours to meet friends & a chat."*

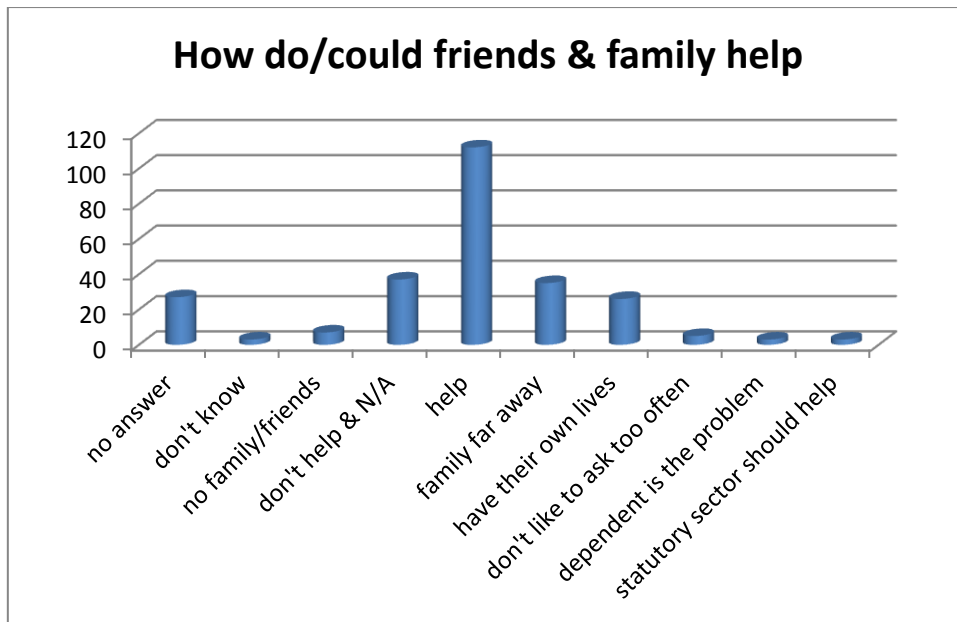
How do / could friends and family help

Three carers said that supporting carers is the duty of the statutory sector and not the family. However almost half (49%) say that their family and /or friends help them, although this is not always on a regular basis because the family live a long way away (15%). A number of the carers also mention the fact that their family/friends lives of their own e.g. working and/or bringing up children (11%), implying that is not possible or fair to expect them to help a lot.

"Family support as much as they can. But my 3 children are all in full-time employment and are raising their young families as well."

And a small percentage (2%) does not like to ask too often.

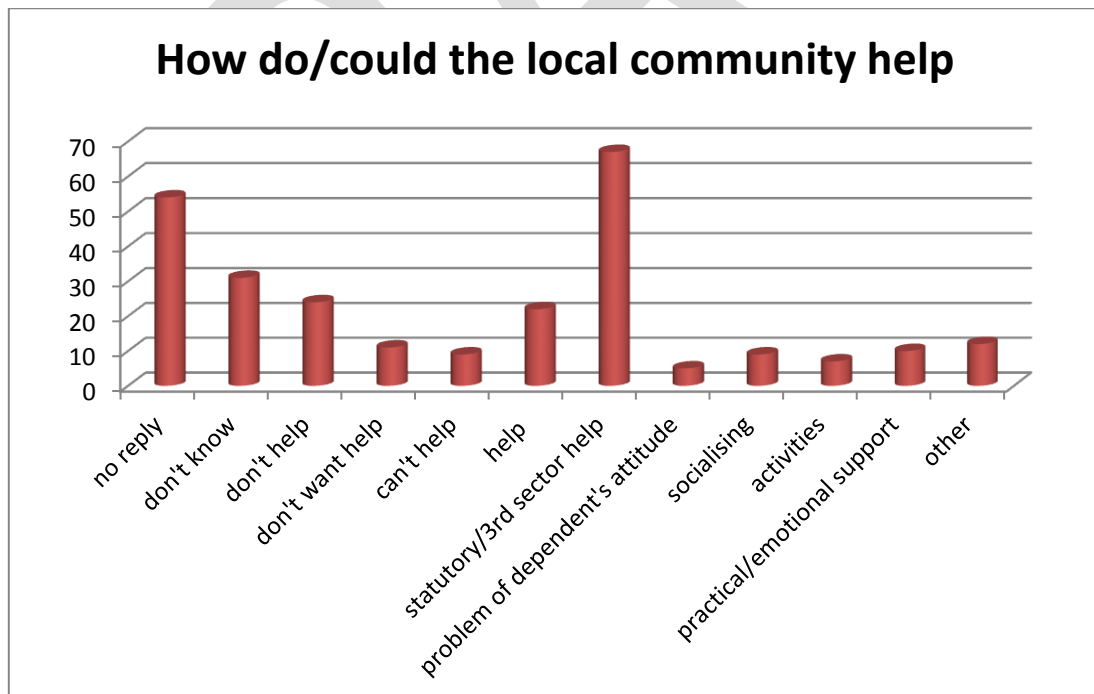
" Family all live in Birmingham. Friends and neighbours always offer but you do not want to become a nuisance."



Sometimes, the problem once again is the attitude of the dependent

" I have no family locally and she had alienated friends & neighbours by her attitude towards them. My son has come to stay in the past but she has been so horrid to him he refuses to support her now. My daughter lives in Suffolk with her family and rarely comes home - also due to Mother's attitude"

How do / could the local community help



By not answering, or saying they did not know, or that no help was available, or they did not want help, or it was impossible for the community to help them, there was a negative response from most of the carers (52%) to the question how could the local community help.

"We are a private family and prefer to remain that way. My wife's needs are high therefore community could not help, nor would we want everyone to be aware of our situation. "

It seems that this is the most challenging questions with 30% mentioning services which are provided by the statutory sector and the 3rd sector, rather than the local community. However this is not true in every case, some of the carers mention members of the chapel calling round for a chat, or neighbours who help, sometimes by doing little things

" They do help by greeting us with a smile when we take our daily walk & stop for coffee. At our age that is much appreciated - more than that our need is small."

11% of the responses refer to practical and emotional support, the need for socialising and activities, which are all the sort of help that could be provided by the local community, if the carer and the cared-for are prepared to accept it,

" I don't think my husband would accept help as he sees himself as a very independent person and only wants to care for him".

Often the carers are thinking about socialising and activities for the cared-for but, at the same time, this support would help them as well. Unfortunately transport can be a problem for a lot of people, particularly in rural areas.

" More help needed in villages. Why can't local halls be used for meeting etc like keep fit. We do go to Pwllheli for up & go classes, not so good in the winter waiting for buses etc & winter time is when we need more support."

Some carers note that they cannot join in local activities because no one is available to be with the dependent.

Perhaps less than a quarter of the carers understood the question i.e. who or what is the local community, and usually they report positively of the support available there, including the following, which is a great example of how the local community can help:

"Because my husband is a partner in the farm he didn't get help to adapt the house - the local community raised money in order for us to make a wet room for him." (translated from Welsh)

To conclude

Although the carers who answered the questionnaire do not reflect the age of most of the carers in Gwynedd, which is between 45-64 years of age according to the 2011 Census, the challenges that they note and the support needed is relevant to many carers of all ages. A lot of research and surveys have confirmed that caring causes fatigue and strain which has a negative effect on carers' health, particularly their emotional and mental health. We are conscious that it is essential for carers to have practical help, such as help from paid carers, and sufficient respite breaks. Unfortunately the questionnaires show that not enough support is available to all carers at the moment,

In reading the responses, it is obvious how unique is each caring experience, so the ideas behind Ffordd Gwynedd and the assessment 'What matters' go in the right direction. The importance of family, friends or neighbours as support for carers is something else which is obvious. When this support is available regularly; the carer feels better, has sufficient respite and is able to share the experience with those who are close to them. This is an experience completely opposite to the large number who fell under strain, tired and lonely. However, unfortunately, a number of carers and

their families expect the statutory sector to help rather than thinking about the informal help available from family, friends and neighbours.

There are a lot of carers in Gwynedd who need support; how to provide it is the challenge, and by whom is the question.

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