

carers



SUPPORT FOR THE
ISLAND'S CARERS

Healthwatch Isle of Wight Unpaid Carers Report 'Paying the Price'



healthwatch
Isle of Wight

Acknowledgements	3
Executive Summary	4-5
Introduction	6-7
Context	8
Local Context	9
Methodology	10
What works	11
Our findings	11
- general practice	12
- hospital inpatient	13
- hospital outpatient	14
- paramedics and emergency health care	14
- respite and social care	15-17
- mental health	18-19
- occupational therapy	20
- physiotherapy	20
- podiatry	20
- dentist	20
- dementia services	21
- crisis support	22
- isolation	23-24
- Accessing services	25
- carers shaping policy and services	26
- carers assessments	27
- young carers	28–30
- safety and quality of life	31
- accessing services;	
linking to communication and assertiveness	32
- peer support and mentoring	32
- experiences of health and social care services	33
- what works well in health and social care	
services	34–35
- what would make your life and those who	
you care for better	35
Conclusion	36-37
Recommendations	38
References	39



Healthwatch Isle of Wight is a local independent consumer champion for health and social care which also provides a signposting service for the public.

We have an important role in assessing the quality of local health and social care services and holding providers and commissioners to account. We speak and listen to a wide range of people to get a broad picture of local experiences.

Acknowledgements

Healthwatch Isle of Wight is indebted to the many carers who shared their stories with us, both individually and at various carer support groups around the Island.

We are very grateful to the team at Carers IW who introduced us to carers and helped facilitate the interviews.

Our gratitude also to the Stroke association who allowed us to join their coffee morning and to learn more about the experiences of carers who use their services.

We would like to thank the team from the YMCA Young Carers Project and a local primary school who advised on the issues that young people face and how it affects their lives.

Thanks also to People Matter IW who have allowed us to attend their service user groups and observe themes as they emerge.

Local Healthwatch has a range of statutory powers and links directly to both Healthwatch England and the Care Quality Commission (CQC)

Executive Summary

Healthwatch Isle of Wight identified support for unpaid carers as a priority for further work in 2015, following an increase in Feedback the previous year on this subject. Support for unpaid carers also came top in the Healthwatch Isle of Wight prioritisation survey in the same year, with many people expressing a view that Healthwatch should explore this topic in more detail.

This report sought to find out whether the challenge of meeting the needs of carers is being met on the Isle of Wight and to understand more about the experiences of carers and how their role impacts on their lives on a day to day basis. But perhaps most importantly, we identified ways in which the role of unpaid carers can be improved both for the carer themselves and the person they support.

We spoke with a wide range of carers from all age groups and backgrounds and we found that despite a wealth of policies and commitments in support of unpaid carers both nationally and locally, carers often found themselves isolated and without the support they needed. They were not recognised or valued as a carer with health and social care professionals and in some cases particularly within mental health services, professionals excluded them to the extent that they were unable to care effectively for their cared for person.

Carers for people with a mental health condition felt particularly isolated, even if they attended a group, due to the perceived amount of stigma attached to mental health. It is notable that the current Mental Health Strategy makes no mention of carers.

What was notable was how selfless carers were, putting the needs of their cared for person before their own and this was especially true when it came to taking care of their own health. We heard of one instance of a carer putting off treatment for cancer until their cared for person had died.

The 2011 Census Indicated that 16,420 people on the Isle of Wight provided at least one hour of unpaid care per week, meaning that 11.9% of the total Island population had a caring responsibility.

In comparison, the South East (9.8%) and England (10.2%) both had lower levels of unpaid car provision.

The most important priorities that carers identified for the cared for person were safety and quality of life, however providing personal care, emotional and practical support also featured heavily.

We found that there was a clear divide between carers who knew through assertive natures, experience or their professional background how to get services to work alongside them, and other carers who felt that they were just at the 'mercy of the system.'

We also found that the quality of support services for carers was recognised and appreciated, however, the level and longevity of this support was often not enough for carers needs. Respite services were particularly valued by carers, however, whilst all the people we asked had varied interests and hobbies, time to spend on them during respite was impacted by having to do mundane tasks such as shopping, visiting the optician and completing household tasks. Almost everyone we spoke to was fearful of the introduction of charges for this service, particularly as their cared for person may refuse to pay.

What next?

This report will be shared with the Isle of Wight Council and the Isle of Wight Clinical Commissioning Group and we are pleased that the findings contained within this report will feed into the refresh of the IOW Carers Strategy.

Among the recommendations we have made to local providers and commissioners of services, we have expressed a wish for the role of unpaid carers to be recognised and valued by professionals and for peer support to have a greater focus within service provision.

We have also requested a review of respite provision for younger disabled people and the implementation of a more 'user friendly' carers assessment form.



Illnesses and conditions that affect loved ones are described by the MS Society as unpredictable and uninvited guests; that arrive in a person's life and those around them and are there to stay. They turn husbands, wives, mothers, fathers, daughters, sons, relatives and other friends into carers.

Carers are people who can spend significant amounts of time each week providing un-paid caring and support for loved ones, who are ill, frail, disabled with mental ill health or substance use issues.

Many carers don't see themselves as carers. It takes carers an average of two years to acknowledge their role as a carer. It can be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care.

There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Those providing high levels of care are twice as likely to have poor health compared to those without caring responsibilities. With an ageing population, when more people are living longer, but with poorer health, it is imperative that unpaid carers are supported properly to fulfil their role and maintain their health.

Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's ability to support the cared for person and could lead to the admission of the cared for person to hospital or residential care. 84% of carers surveyed for the 2013 State of Caring Survey (produced by Carers UK), said that caring has had a negative impact on their health, up from 74% in 2011-12. Carers attributed their health risk to a lack of support, with 64% blaming a lack of practical support





The 2011 Census indicated 16,420 people on the Isle of Wight provided at least 1 hour of unpaid care per week, meaning 11.9% of the total Island population had a caring responsibility. In comparison, the South East (9.8%) and England (10.2%) both had lower levels of unpaid care provision. Of those people providing unpaid care, 4,104 provided 50+ hours of care per week (3.0% of the total population), higher than both the South east (2.0%) and England (2.4%).

Source: ONS - www.neighbourhood.statistics.gov.uk

Carers need a strong skill set to enable them to fulfil their roles. This includes having knowledge about the condition affecting the cared for person, knowing how to care effectively and safely, including supporting the people they care for with personal care. They have to deal with statutory services, legal matters and frequently the benefits system. They often have long term conditions themselves, which could affect their ability to deliver their caring role. This on top of running a household, frequently caring for children or other relatives and often holding down a job. The pressures can be enormous and time out for themselves is seen as a luxury. It is also an isolating and lonely role.

This report seeks to find out whether the challenge of meeting the needs of carers is being met, to understand more about the experiences of carers and how professionals from health and social care services treat and interact with them. Most importantly to identify ways in which the role of unpaid carers can be improved, both for the carer themselves and for the people that they care for.



Context

There is an enormous range of evidence and policy supporting the needs of un-paid carers. Primarily, there is the recognition that carers save the NHS and social care services a huge amount of money each year. The 2011 Report by Carers UK - 'Valuing Carers' found that the economic value contribution by carers was £119 billion, more than the then total cost of the NHS, and a rise of 37% since 2007. On the Island the 16, 067 carers providing care, was valued at £303.1million per year.

Although carers can be of any age, it should be noted that many are reaching older age. On the Island the survey of adult carers completed by the IW Council for the Health and Social Care Information Centre (HSCIC 2014/15) found that over half (55%) were aged over 65. The HSCIC report only includes carers aged 18 or over. There are local estimates of over 300 young carers registered for support provided by the YMCA.

The NHS England - Five Year Forward View clearly articulates the need for supporting carers:

'Two thirds of patients admitted to hospital are over 65, and more than a quarter of hospital inpatients have dementia. The five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself. We will find new ways to support carers, building on the new rights created by the Care Act, and especially helping the most vulnerable amongst them - the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. This will include working with voluntary organisations and GP practices to identify them and provide better support. For NHS staff, we will look to introduce flexible working arrangements for those with major unpaid caring responsibilities'

The NHS England Commitment to Carers (2014) makes specific pledges to carers; these are:

"Recognise me as a carer (this may not always be as 'carers' but simply as parents, children, partners, friends and members of our local communities)"

"Information is shared with me and other professionals"

"Signpost information for me and help link professionals together"

"Care is flexible and is available when it suits me and the person for whom I care"

"Recognise that I may need help both in my caring role and in maintaining my own health and well-being"

"Respect, involve and treat me as an expert in care"

"Treat me with dignity and compassion"

Despite the above, the Carers UK Report 'Caring in Later Life' (2015) found that carers had mixed experiences of health and social care services. For health Services whilst 44% said that experiences were positive 14% found them negative.

Regarding contact with social care professionals, 44% had positive experiences with 15% negative. This is in addition to 4 in 10 carers having experienced difficulties in the way that health and social care services work together

This report also found that although 70% of carers come into contact with health professionals, health professionals only identify about one in ten as being a carer. 66% of carers feel that healthcare staff don't help to signpost them to relevant information or support, and when information is given, it comes from charities and support groups.

The Department of Health's mandate to NHS England includes ensuring that the NHS becomes significantly better at involving carers as well as patients in care.

Local Context

The Isle of Wight Council and Isle of Wight Clinical Commissioning Group have published the 'Working Together With Carers' Strategy 2013-16. This joint strategy is to reaffirm their commitment to continue to seek out and improve the lives of carers. The priorities are:

- Identifying and including carers
- Providing information, advice and training
- Carers shaping policy and services
- Peer support
- Carers breaks
- Access to work and training
- Access to benefits
- Crisis support
- Access to health and wellbeing
- Support for children and young carers



The strategy was based on consultation which found that 55% of carers did not know who to contact in a crisis, 68% had not had a carers assessment and 89% reported that caring had an impact on their general life.

Support for adults caring for adults is delivered locally through Carers IW, the Stroke Association, the sitting service which is currently provided free of charge, together with other smaller initiatives. Support for young carers is delivered through the YMCA. There is an acknowledgement that these services for adults, children and young people need to work together especially in the transition of young people to adult services. Also that all services should be flexible in their approach in order to respond to the variety of ways in which those with caring responsibilities can be best supported.

Methodology

To gain the best understanding of the issues that carers face as part of their role, it was decided that the best approach would be to attend a variety of community groups, where carers would be present.

Alongside the feedback that Healthwatch Isle of Wight had already collected, this enabled us to identify particular themes and trends with regards to the effectiveness of support currently available to carers on the Isle of Wight.

Carers IW then supported us to contact individual carers who were currently caring for an individual and who wished to share their experiences with Healthwatch Isle of Wight, with a view to improving the future provision of local services for unpaid carers.

We spoke with individual carers, from a wide range of ages, financial circumstances and with their own health issues from across the Island, living both in towns and villages as well as more rural and remote areas. The people we spoke to were caring for others with a range of disabling illnesses and conditions, which affected their daily lives in countless ways.

We looked for common issues that could be addressed rather than trying to seek to solve the problems and issues of all. All experiences shared have been recorded onto the Healthwatch Isle of Wight Customer Relationship Management system (CRM).

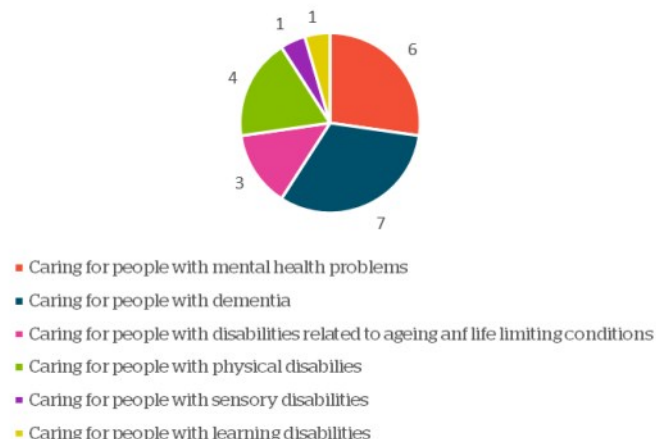
Those who we spoke to who wished to make specific complaints have been signposted to the Healthwatch advocacy partner SEAP.

In numbers:

14 Outreach Sessions - including Carers IW Respite weekend during November 2015

20 conversations were held with individual carers

Caring for people - in numbers



What works

There is evidence which shows that effective support to carers usually goes beyond a single intervention and encompasses good quality mainstream services, and sensitive and carer-aware professional practice (across health, social care, education and all local services). Importantly, evidence shows that a joint strategic approach by health, local government and voluntary organisations is needed for local populations to develop and commission a range of local services suited to the local needs of carers and people using services.

<http://www.nkm.org.uk/wp-content/uploads/2012/11/The-UK-Care-Economy-Improving-Outcomes-for-Carers-4.pdf>

Our findings

During our conversations with carers, we built on the themes we had identified earlier and sought to find out about carers individual caring commitments, the effect these had on the quality of life of the carer and exactly what life is like as a carer.

We also asked about their experiences with specific services - what had worked well and equally importantly, what had not worked well and our findings are documented throughout this report.

Findings—General Practice

General Practitioners are universally accessed by the population. They are the first port of call for any health worries and act as referrers and sign-posters onto other services and treatments. We asked for both positive and negative experiences with GP's and staff at their practices.

When asked what worked well in health and social care services, some carers named their GP as the best service, using descriptions such as;

'brilliant, supportive, listening, sharing information and straight talking'

Others were described as :
'helpful and insightful'

These positive remarks generally came from carers who had been able to build a successful professional relationship with their GP.

Others remarked on the lack of continuity as they never saw the same doctor. In these cases most GP's were unaware of the person's caring role. Many remarked that it would be helpful if they were flagged as a carer, for example, in order for GP's to share and receive relevant information about the cared for person in order to assist with diagnosis and treatment. It was generally felt that being identified as a carer would support professionals to have a greater understanding of their needs, for example, carers may not be able to attend early appointments due to their caring role. They may also require additional emotional support during appointments.

Good practice was noted at Sandown Medical Centre where appointments for elderly people were clustered, for example, GP appointments were synchronised with clinics, tests and so on, to try and reduce the number of repeat visits. Also at Tower House surgery in Ryde where one GP was responsible for all patients with dementia.

For those caring for people with mental illness, finding the right GP was imperative. Carers reported that the right attitudes and treatments could make a huge difference for their cared for person, whereas unsympathetic and judgemental GP's could adversely affect outcomes for their cared for person and themselves. Community and District nursing and Matrons received a great deal of praise for their flexible approach and attention to detail. However, one carer commented that it was harder to access them now and attributed that to the change to locality working. Another had to organise her own dressing for her cared for person as none were available that were suitable.

A relatively new service the Care Navigators received praise from one interviewee in giving good advice and signposting. The carer could not imagine how else people could learn how to access services. However, another said that they could not tell her anything she did not already know. As this is a new service it is hard to draw any conclusions from these two pieces of feedback, but close evaluation of the service would be advised.

Hospital Inpatient:

Carer reported that whilst her mum was in rehab in St Marys, she suffered a number of urine infections, was repeatedly asked whether her mother had dementia, which was not the case.

Her mum was in a single room for 3 weeks in rehab following an operation, she couldn't even watch TV, read, or listen to the radio so this was totally isolating and impacted on her recovery.

Carer says it was 'cruel' and should a similar situation arise she will discharge her mum and take care of her at home.

This recollection was similar to several others we heard from carers of older people. Urine infections seem common and the symptoms attributed to dementia when this is not the case.

Several carers of people with dementia told us that staff seemed disbelieving of the amount of pain these patients could be in, and that their concerns were dismissed.

We also heard several stories where we believed a complaint could be made. In all of these circumstances the carers refused our offer of support to access the complaints advocacy service, SEAP.

This was for one or more reasons,

most commonly because the carer did not have the time or energy to pursue a complaint. There was also the fear that a complaint could lead to retribution and a reluctance to further help the cared for person. One had complained previously, and said that as the complaint had never been resolved she had no faith in the system.

Others worried about their cared for person whilst they were in hospital, particularly if they did have dementia, or were very ill, as the excerpt above shows. One witnessed another patient calling, 'Toilet, toilet...' repeatedly without staff responding. Others stayed with their cared for person as much as they could in order to ensure that they were properly looked after.

We heard a distressing experience relating to end of life care. The cared for person was unaware that they were nearing the end of their life and hospital staff discussed palliative care in front of them. The carer had to move to another part of the ward to speak to staff, to ensure that messages about end of life care could be given sensitively and appropriately. This feedback was not isolated and illustrates the fact that sensitive and compassionate communication is key to achieving the best outcomes for both carers and the people they care for.

Hospital Outpatient:

A key issue here identified by carers we spoke to, was the lack of co-ordination around out-patient appointments. They were frustrated that they had to return to the GP for further referrals for other services and could not understand why hospital departments could not refer internally - they were also aware of the increased workload that this created for GP's. Another issue was having to return to the GP for changes to medication, they saw this as another increase to GP's workloads, and another task that they had to complete also.

The importance of the carer being able to provide clarity and reassurance to their cared for person was not always met at hospital outpatient appointments. They were not always recognised as a carer and encouraged to attend the appointments. This made them fear that their cared for person had not told staff all symptoms, or understood all questions asked of them.

A carer told us that much more time was needed for older people at appointments, especially where minor procedures were carried out, so that they could explain and reassure their cared for person. This was especially true if the cared for person had dementia, learning disability or a mental health condition.

Paramedics and emergency health care:

All comments received regarding the paramedic and 111 service were positive, their role being much appreciated together with the calm and positive attitudes of staff, even supporting carers to learn their techniques for example, in supporting someone with a panic attack.

However, there were negative comments regarding treatment and attitudes in A & E. One carer heard staff commenting that her disabled cared for person was drunk, and this was why they had fallen, which was untrue. Another reported waiting 12 hours for treatment for their cared for person, then being told that was nothing wrong. Days later they were admitted as an emergency via air ambulance to Southampton. In the latter case, we suggested a referral to SEAP to make a complaint, however, the carer said that they had complained in the past without any real response and were too tired and busy caring to pursue another.

Respite and Social Care:

'2 hours is no good for me'

Currently, some carers, particularly of older people with dementia, can access two hours per week free sitting service which they value as respite from their caring role. There will be the introduction of means tested charges from April 2016.

All the people we spoke to who cared for people with mental illness did not access this service. For younger disabled people it was questioned whether a sitting service was appropriate.

At carers support groups, people often said that they were 'the lucky ones' as they were able to access the groups and that there were many others who were unable to. Any accessing the 'sitting service' remarked that the time was just too short and too fixed for their needs. They stated that although they had hobbies and interests that they would like to pursue when the cared for person was using the sitting service, they were unable to do this either both because the time was inappropriate (accessing an evening support group when the sitting service was during the day), or because they had other appointments to attend for themselves during the time allocated. Several remarked that they just did the shopping and one carer drove to the beach and caught up on sleep in their car. The free sitting service does in spite of this remain a highly valued service.

Carers are already becoming fearful that with the introduction of charges for the sitting service and flat rate respite, that their cared for person will refuse to pay and they will be left without an important lifeline. This service does try to match paid carers to the cared for person's needs and many cared for people currently use this service to go out walking, bowling, join other groups, cooking at home, shopping, cup of tea out and about. The service can be arranged for the evening if the care agency have available staff - it needs to be prearranged and many carers seem to be unaware of this. It would be easier for people if this valuable service was discussed and referred to as a respite service, thus squashing any preconceived ideas.

Some remarked on the pressures to home care services which provided the sitting services. Carers from these services could arrive late and appear rushed. Carers were aware that staff from these services were often under pressure, with mileage and travel time excluded. Others noted that where they had made specific requests for carers, for example, not wearing uniforms or just the same carer every week, these were not complied with. It was also noted that there seemed to be a high turn-over of staff, leading to a lack of continuity for the cared for person.

Most carers were happy with the residential care homes which provided respite for their cared for person. We received a great deal of praise for the Adelaide, Northbrooke House and Merrydale.

It was noted that it was not always possible to access a preferred setting. This was because it was acknowledged it was more cost effective for homes to have full-time permanent residents and in the case of the Adelaide; that they would not say when there were vacancies in advance making it very hard for the carer to book holidays.

Settings were generally designed for the respite of older people, meaning that it was unsuitable for the needs of younger people. Carers stressed that if they were having respite they wanted to be confident that their cared for person was not just safe, but that they were also enjoying the break.

We heard a few stories where respite residential care had been unsafe, in these cases we signposted the carer to the relevant safeguarding authority.

"The cared for person was receiving respite in a care home. He rang his carer one evening saying that he had been to St Marys for a heart check up. His carer knew that there was no check up planned and was worried. It transpired that the cared for person had had chest pains and had been taken by ambulance to hospital. The care home manager told the carer that staff had rung her but that she had said she wasn't interested. This was not true, the carer had been at home all day, no phone call had been made. When the carer challenged this the home manager said it had been hectic (over lunchtime) so there may have been a delay in calling. The carer was frustrated as no-one seemed to take responsibility for this lack of communication, she asked what would have happened if the cared for person had died and was told 'I am sure someone from the hospital would have rung you.' she later made two written complaints to the care homes. The first was ignored, the second complaint, the response cited confidentiality as the reason for not responding."



Mental Health:

If carers are 'Cinderella's' in our society then carers of people with mental illness are 'Cinderella's Cinderella'. There is no mention of carers within the current local mental health strategy and whilst we were aware of an online support service, we did not meet any carers who knew of it or had accessed it. For many carers, if their cared for person did not wish to access services, then they are very much alone. Mental illness affects people of all ages and whilst health and social care services are willing to share and receive information where dementia is involved this is much lacking in mental health services, the crux of this being the lack of recognition of carers for people with mental illness.

"They hide behind confidentiality and then blame me for what happens next..."

Carers of people with mental illness care be more isolated than those caring for other conditions. Everyone we spoke to said that there was still a stigma attached to mental illness. Also that their cared for person was reluctant and unwilling to socialise or receive friends and family, making the carer more isolated. In other instances, the behaviour of the cared for person meant that friends and relatives were discouraged to call.

The carers are called upon to provide constant emotional support and reassurance, but many said that they did not feel like 'real' carers; who provided both practical and emotional care.

"I do everything and nothing for him"

"I keep her alive"

The carer often had their own anxieties seated in the fear that they did not know if they were doing the 'right' things for their cared for person. This was exacerbated by professionals being unwilling to share information on diagnosis and treatment for the cared for person.

Both carers and cared for people were often unclear about pathways of care in mental health services and what their expectations should be. Carers were often afraid that if they did not attend appointments with their cared for person, then services would not hear the 'whole story, the extent of the mental illness and its effects. At least one carer had given up work and their independence to try and ensure that their cared for person got the care and treatment they needed.

Fears were also expressed over the frequent staff changes, use of locums and junior staff meant that their cared for person did not get the care and treatment they deserved, and continuity was subsequently raised as an issue.

For those with both mental and physical illnesses, the issue of 'parity of esteem' was raised again and again. Whilst carers were not familiar with the phrase, when the concept was explained to them they agreed that this often summed up their concerns. More than one person with a disabling physical illness was told by mental health services that they could not be helped.

In the main we spoke to people who were caring for people with longstanding mental illness, in most cases the only treatment was medication, with one having been prescribed Lithium for over 15 years and several being prescribed Seroxat for over 20 years. There was a great deal of confusion on how other therapeutic services were accessed, and this sometimes then led to a reluctance of the cared for person to access them.



Carers were asked to comment on any other services that their cared for person had received and their thoughts are summarised below

Occupational Therapy:

We received a very mixed picture of occupational therapy, with some rating the service very highly, especially for cared for people who were older, had dementia or were nearing the end of their lives. For physically disabled working age people again, the service was rated very highly. For those with a temporary disability, the service seemed far less helpful, and we were told of one instance where this led to a delayed discharge and the wrong equipment being delivered.

Physiotherapy:

The views we received were from carers of older people. They found that the service was too little too late and that there was a tendency for professionals to write off the elderly;



'She will never walk again anyway'

Podiatry:

Three very different pieces of feedback were received; very positive for working age people and again dismissive of the needs of the elderly.

Dentist:

We found that people with mental illness were often reluctant or unable to attend the dentist. For those with debilitating conditions alongside mental ill health we heard several experiences where they had had several teeth in need of attention, but could not access services for this reason. Carers told us that this area was fraught with difficulty and they had to provide a huge amount of emotional support to encourage and enable their cared for person to attend.

A carer of a person with a learning disability told us about recent issues with the booking system and lack of reminders at Arthur Webster Clinic. The carer noted that whilst many NHS and private practices now sent text reminders, this clinic did not, yet dealt with people with additional needs. The same carer also noted the lack of hygienist at the clinic.

Dementia Services:

For those whose cared for person attended the Memory Service delivered at the Riverside, many carers were complimentary both on the outcomes for the cared for person and how much they enjoyed the sessions, but also for how staff members included the carer and made them feel welcomed and valued. They also provided expert advice on how to support people with symptoms of dementia. One told us that it was the only time that she felt that her cared for person was safe and provided essential respite for her. Others told us that they would like sessions to continue, but were aware of budgetary pressures on the service together with high demand.

Several mentioned that their cared for person would not attend, on more than one occasion this was because they did not like the environment. Others did not see themselves as benefiting until 'it was too late'. Alzheimer Cafés and the new Ace 7 Café for early on-set dementia all received praise as an essential service by those who attended them. Memory Clubs run by other organisations were perceived as too expensive, and people either looked for alternatives or chose not to use this service.

Caring responsibilities do not cease when a cared for person goes into full time residential care. We met one carer who was having to pay close attention to all medication prescribed and its side effects following several failures of medication management by the care home. The carer had complained about these issues to the GP surgery, the care home and local safeguarding team, but in the event, nothing could reintroduce her faith in the home, that her cared for person would be safe. This carer is now looking for an alternative setting for their cared for person, with support of Carers IW and an independent advocate.

There was a feeling amongst those that talked to us that forward planning for cared for people with dementia often fell short and they were unsure what lay in the future, what their expectations would be and what else they could learn to be able to continue to support their cared for person at home for as long as possible, when asked how they coped, overwhelmingly they said,

'I just get on with it'.

Crisis Support – Priority 8 of Joint IW Strategy

'I'm exhausted and scared for the future'

Although this is a priority area in the Isle of Wight Carers Strategy, our research would indicate that there is still much to do. Crisis support needs to ensure that the needs of both the carer and the cared for person are consistently met, when a crisis situation occurs.

Where possible carers relied on other family members to look after their cared for person. In some cases however, this had created intolerable burdens, especially on young people looking after their parents.

Too often we heard that a crisis led to paid care being provided. If this care had been provided earlier, then the crisis might have been avoided. Where crisis support had been arranged, this was appreciated by the carer, but it was rare to hear this.

Inappropriate settings for respite, especially those arranged when a crisis occurred, meant that carers would not take all the crisis respite that they had been allocated.

An overarching theme throughout the conversations was the need for cared for people to have regular respite care.

One carer told us that when they mentioned their own long term condition and the possibility of needing crisis support to the Social Worker, they were told "I'll make a note." Later, both carer and cared for person became unwell, the GP called and rang first response (local authority), but no help was offered.

Others told us that they would not have known where to start to find out how to access support if family or friends had not helped, this links to access to advice and information.

For carers of people with mental health issues, the behaviour they witness can be terrifying. One carer told us how she felt she had no option but to make her adult child leave her home, only having to take them back when there was no other provision for them.

'It's no good the council saying there are no properties, he needs somewhere to live'

We were saddened to hear of a carer who was unable to secure carers to provide nursing care to her dying partner, due to the location of where they lived. This meant that they died against their wishes away from home.

Isolation - links to Priorities 1, 2, 4, 5 & 9 Of the Isle of Wight Carers Strategy

We asked carers about the impact of caring on their emotional and physical wellbeing.

A 2013 report by the Royal College of General Practitioners found that 40% of carers suffered depression or were at risk of other psychological problems and that if a carer became unwell and unable to continue caring, then the cost to the NHS increased dramatically. Despite this we found that isolation and loneliness were key issues that carers had to face day in, day out. At carers support groups, we heard many times carers saying that they were the lucky ones, as they were able to take the time out to attend. Others could not arrange or afford care to enable them to do this.

Support Groups are good, but you are still on your own'

A significant number of carers who are supported by Carers IW, care for someone with mental illness. They have the opportunity to participate in support sessions, specific support groups, solution focused sessions, creative and holistic sessions etc, but carers of people with mental health problems felt particularly isolated. One said that she was embarrassed to tell friends, another felt that whilst she attended a support group, the issues she faced seemed trivial compared to others who were caring with physical conditions and dementia.

Mental illness still carries an element of stigma, and the unique nature of the way it affects individuals meant that carers were unlikely to find peers easily even if they wanted to share experiences. Whilst other strategies locally, including the End of Life and Dementia Strategies make specific provision for carers, there is none in the Mental Health strategy.



'Nobody signs up for this'

For carers of people with dementia the effects were equally profound. They told us that friends would shun them because they were afraid of the condition. They suffered a great deal of sadness in watching their loved one decline. They became frustrated with dealing with their loved one, having to repeat themselves over and over again. Sometimes the behaviour of the cared for person was very difficult to cope with and this could include swearing and rudeness, both at home and out in the community. Those who had attended dementia training, found it useful. In addition, those that attended Alzheimer Café's including the ACE 7 Café very much valued the resource.

They told us about the 'huge responsibility' of caring for someone with dementia, their paramount concern without exception was to make sure that their cared for person was safe, with quality of life equally as important.

The sitting service and flat rate respite was valued immensely. However, almost everyone we spoke to was fearful of the introduction of charges for this service; particularly as their cared for person may refuse to pay.

'Costs go up, but there is no more money coming in to pay for it'



Across the board for those of working age, giving up work to care full time had a negative impact, through giving up their independence. They spoke of voluntary activities as something to "Keep my brain working". Many had sought social contact through volunteering. Team-working helped combat the feelings of isolation and they did not feel guilty for taking time out if they were helping others.

An invitation was offered to attend the Carers IW respite weekend during the course of this work. Carers respite weekends are residential for those who choose and who are able to take up places, with others attending for the day or when they can. The days are full of warm relaxing places, of lovely scents and appetising food. Therapies and craft activities are offered in comforting surroundings. It offers a real 'time out' for those attending. Feedback was not sought during the weekend, nevertheless some carers were keen to share their experiences with us during this time. Carers respite weekends are organised quarterly, and very much on a shoestring with all therapists and crafters giving their time freely. Volunteers also complete a multitude of tasks to make it happen, alongside the small staff team. Carers IW has 25 volunteers, including trustees, who enrich the work of paid staff and bring expertise through their previous careers and experience, with many being former social workers and carers themselves.

Unfortunately, Carers IW are currently unable to find a suitable and affordable venue to offer the residential side of the respite, however, they are offering the full day on a Saturday as well as locality based mini respite days.

Accessing Services – Links to Priorities 1 & 2 IW Joint Strategy

“Nobody tells you who can help”

“someone from church told me about Carers IW”

“If you’d asked me two years ago I wouldn’t have known where to start”

All the carers seemed to have reached some sort of crisis before any formal support was sought. There seemed to be no standard access route with many relying on friends and family to signpost and support them.

As previously stated we heard both positive and negative reports of the new care navigators, this would seem an obvious route into services.

Information sessions and marketplace events did not seem an effective method of raising awareness, with only one carer we spoke to having attended such an event and then finding the event, ‘A waste of time’.

One carer said that on diagnosis of a condition, i.e. dementia, an information pack should be supplied. In addition, the ability for a carer to access a service for themselves is dependent on being able to leave the cared for person or having adequate respite care to be able to do so.

As far as ongoing access to services, there was a growing fear of impact of the introduction of means tested charges for the ‘sitting service’. Also the cost of Memory Clubs which was seen as prohibitive by many. Carers we spoke to were also aware that where there were Personal Budgets, the cared for person could refuse to pay for these activities and leave them without much needed respite.

Healthwatch is aware of the initiatives through My Life, A Full Life and the Islehelp service that could address many of the issues outlined above. All these services are still in relative infancy, so only time will tell how effective they prove to be for those that need them most. NICE (LGB 14) Advice (Improving access to health and social care services for people who do not routinely use them, Jan 14), recognises that some groups find it harder to access services and these include lifestyle characteristics such as being a carer. Thought should be given on how to make these services more accessible to carers.

Dealing with services – Link to IW Carers Strategy Priority 4

What became clear in our interviews with carers was that some were more able to obtain services and help for themselves than others. This was not related to their education or background or indeed to the length of time that they had had caring responsibilities. It would appear that it was in many cases due to the naturally assertive nature of the carer.

However, there were also some clear examples which emerged where peer support, from those who were more experienced at caring could provide an invaluable source of practical and emotional support. The potential of Peer Support should be explored further including face to face support and through the use of other mediums including social media.

Carers shaping policy and services – Priority 5 of the IW Joint Strategy

This was not an area that we concentrated on when speaking to carers individually and at the support groups we visited, however Healthwatch staff regularly attend the carers group meetings at People Matter.

It is to be noted that the local authority commissioning officer was regularly in attendance at these meetings and that considerable effort was undertaken to answer issues raised by the group. Other professionals from statutory services also attended on a regular basis, together with representatives from the voluntary sector.

It is a relatively small group of unpaid carers that regularly attend the group. Perhaps this is unsurprising given the demands upon carers in their caring role and the lack of free time available to them. Informally, concerns were raised with us about how representative the group was, and also the need for carers to be members of People Matter in order to be kept on mailing lists. In the light of this, it would seem sensible for other methods to be considered, when looking at ways in which carers can help shape policy and services.

Carers Assessments

I am an intelligent woman but when I read this I felt totally at a loss what I had to do'

Whilst this was not a theme we explored through our conversations with carers, our attention was drawn to the issue of carers assessments, both by the People Matter IW (PMIW) Carers Group, also by Carers IW. Carers IW kindly shared anonymised feedback they had received, with permission from those who had given it.

The carers assessment is 14 pages long and could be perceived as an intimidating document to complete for many carers, especially if they are providing an extensive and time consuming level of care and are not used to completing forms. It was reported that due to some of the language used in the assessment, carers often felt fearful that by submitting the form, the cared for person could be removed and taken in to care. Whilst we understand that there is a plan to simplify the language, carers often need support to complete the form and not just have it posted to them or complete on-line. Carers IW are not currently commissioned to support the completion of these assessments, but are undertaking the role in order to sufficiently support the carers, this obviously causes pressure in other areas of service delivery.

Comments about carers assessment forms:

"feel that they are going to take my mum away if I fill in this form, as each question asks is it satisfactory and sustainable, I am not filling in that."

"I used to work for the council and fill in forms with people and I really do not understand what I should fill in."

"They sent me this form when I asked for help with my Mum, I don't need help, my Mum needs help to get washed and dressed."

"What do I get if I fill in this form, I do not have time to fill in paperwork for the sake of it."

"They have told me if my husband needs respite then I must fill in this form."

"The Care Manager is coming Wednesday and he has told me that I have to complete my form before then. I really have no idea what to put."

"My husband has care to help him wash and dress but this stops after six weeks and the Social Worker said I can manage but I might get some respite if I fill in this form."

Carers IW have been working (through the Ageing Better Steering Group), with the carers commissioner to look at the carers assessment form and they have supported a group of carers to complete a form currently being used within Portsmouth and will feedback on the process at their next meeting in March.

Young Carers

A young carer is a young person (under 18) whose life is affected by caring. The person being cared for will have a disability, long term illness, mental health problems, addiction to drugs and / or alcohol. The person being cared for may be a parent, sibling, other family member or friend, and is not necessarily living in the same house as the young carer. Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers' lives, including their health and educational achievement. Young carers can be bullied and/or socially isolated and this can have an adverse impact on their education and social development. On the Island the 2011 Census found that there were approximately 340 young carers aged 0-15 and that they were providing unpaid care for between 1 - 50+ hours per week. On the Island, commissioned young carers support is currently provided by the YMCA. A small amount of funding is used for respite including attendance at the annual Young Carers Festival. The rest of the allocation of this funding is used to assess the needs of young carers and allocate part-time community based support. This is where support workers have an allocated area of the island providing individualised support to tier 2 (high needs) young carers. Currently 170 (tier 2) young people are offered support from an allocated support worker.

Some young people require short term support with long term positive outcomes i.e. supporting homework strategies, meeting with their support worker every now and again whilst others require intensive support which require a whole family approach and the input of numerous agencies and services. YMCA Young Carers kindly shared the following information from their Young Adult Carers report with us also.

It is notable that there is no specific strategy for young carers. There is mention of the needs of young carers within the Isle of Wight Children and Young Peoples Plan 2014 -17, other joint strategies do not reference the needs of young carers specifically at all, although we understand that plans are underway to address this within IWC Early Help support. The Children `s Society Report 'Hidden from View' found that one in twenty young carers miss school because of caring responsibilities and may have significantly lower educational attainment. The difference between 9 B's at GCSE, if not a young carer to 9C's if they are a young carer is significant. Additionally, this report found that many young carers between the ages of 16-19 are not in education, employment or training (NEET). For those that are, income from employment tends to be lower. Children and young people may avoid services and not ask for help and remain hidden because of family loyalty, stigma, bullying and not knowing where to go for support, this particularly applies where parents have mental health or substance use issues. The Children and Families Act 2014 lays out responsibilities around assessment and support for Young Carers.



For young carers whole family approaches should be encompassed including not making assumptions about a carers ability and willingness to care. It has been found that children are not seen as part of an adult's assessment for support. Also, that disabled adults are not seen as parents. This can mean that children are not identified as young carers and miss out on the vital support they need. No care or support package for a parent or sibling should rely on excessive or inappropriate caring by a young person (Making it Real for young carers - Think Local, Act Personal)

'There is a significantly higher number of **female** YAC (young adult carer) registered with YMCA than **males**, nearly **50%** more. Research shows that this is not a true reflection of society and highlights the importance of engaging young carers from an early age, particularly males.

A significantly high proportion of Young Adult Carers are impacted upon by caring for a relative with mental health issues: **73%** of those aged **19+** and **64%** of those aged **18**.

It needs to be considered that some of these young carers may not have engaged with the service recently and circumstances may have changed. This reinforces the importance of the proposed transition procedure to ensure that any new referrals made to other agencies or services provide accurate and current information.'

Due to the sensitivities involved, we decided that feedback and general concerns and issues from young carers were better relayed by the people that knew them best. This being school staff and workers from the young carers, this way we could also be sure to protect the confidentiality of the young people.

Recent changes to funding means that most respite activities are no longer funded. YMCA successfully fundraise for the many respite activities, in the past year raising nearly £9,000 However, we heard that younger Young Carers feel that it is the time away that really makes the difference and they would prefer local activities that were free, rock-pooling and forest walks were mentioned. This meant that travel costs were negligible and that more could take part on a more regular basis.

Schools are encouraged to set up young carers support groups. We spoke to one Primary School where they had identified and were regularly supporting over ten children aged from 7 years. They told us that the impact of having a sibling with disabilities meant that whilst the other sibling may not be a carer, their life was severely impacted by their sibling and they could lack the emotional support they needed at home. An example of this could be where a sibling with an autism spectrum disorder would not play board games, so that they were never played at home, meaning the other child missed out on this enjoyable activity. Other issues went deeper, a child could have support or health needs of their own and be coping with that alongside caring for a relative with an enduring mental health problem.



One school reported that they were well prepared to support young people, saying that they had been able to create a supportive environment where children were not afraid to say that they were a carer and that this had led to mutual support and no stigma attached to the role. They said that they would like to maintain a safe and caring environment for the young carers upon their transition to secondary school, to support their needs effectively.

There is currently a great deal of work going on supporting young carers into adult carers services, the good practice example given below outlines some of this work.

YMCA Young Carers shared the following:

‘Young male adult carer who is not in education, employment or training, is the primary carer for his mum who has a degenerative condition. Mum’s partner works full time so the young person provides care around the clock. He left higher education last year as it was felt that there was a lack of support around his educational needs and his role as a carer. His caring role has a negative impact on his health and as a result he suffers from depression. He accessed a support service at 18 but the service can only offer help up to their 19th birthday (YMCA Young Carers). The young adult was met by a YMCA support worker to help transition him to another agency which now supports young adult carers (Carers Isle of Wight) and offered support to refer to adult social care, and his application to a local enterprise project (YMCA Futures) to help him with economic wellbeing. At the time the young person didn’t want to access a referral to adult social care. Since engaging in both Carers IW and YMCA Futures he’s been able to feel like he can open up about his situation, and has since been able to ask for help. Services involved are working together to ensure the young adult carer can access the support that is open to him and his family whilst understanding the complex barriers he is faced with. The case is ongoing’.

We understand that a Carers IW worker has now been invited to the transitional interview held with carers who are 18 years of age.

This is dependent on the young adult carer caring for an adult and agreeing to an appointment to discuss their future and this should ensure a smoother transition for the carer between children’s and adult services. Carers IW are planning an information/training day around support for young carers who support people with drug and alcohol problems and this is planned for the next few months.

Safety and Quality of Life

These were two key areas that carers talked about more than anything else and these were the two aspects of caring that they saw as imperative when providing support for their loved one.

We were given examples of how these two are achieved. One carer, caring for someone with dementia said he only ever left them first thing in the morning when they were still in night clothes. This was so if the cared for person left their house, they would be noticeable to anyone due to their state of dress.

Others would seek out innovative ways to address issues, such as the use of adapted sanitary products to dress wounds and reduce pressure. Many were exceptionally strong advocates for their cared for person, even in very distressing circumstances, such as end of life to ensure their best interests, even if they had little support themselves. Others continued to care for loved ones when the nature of their illness, in particular dementia, meant that they could become aggressive and exhibit quite frightening behaviour, and often when the carer could also be aging with their own long term conditions. They went on providing personal care, support and tried to find activities that would stimulate and amuse their cared for person. They encourage and support their cared for person day in day out, and as one said 'I keep him alive' (mental health).

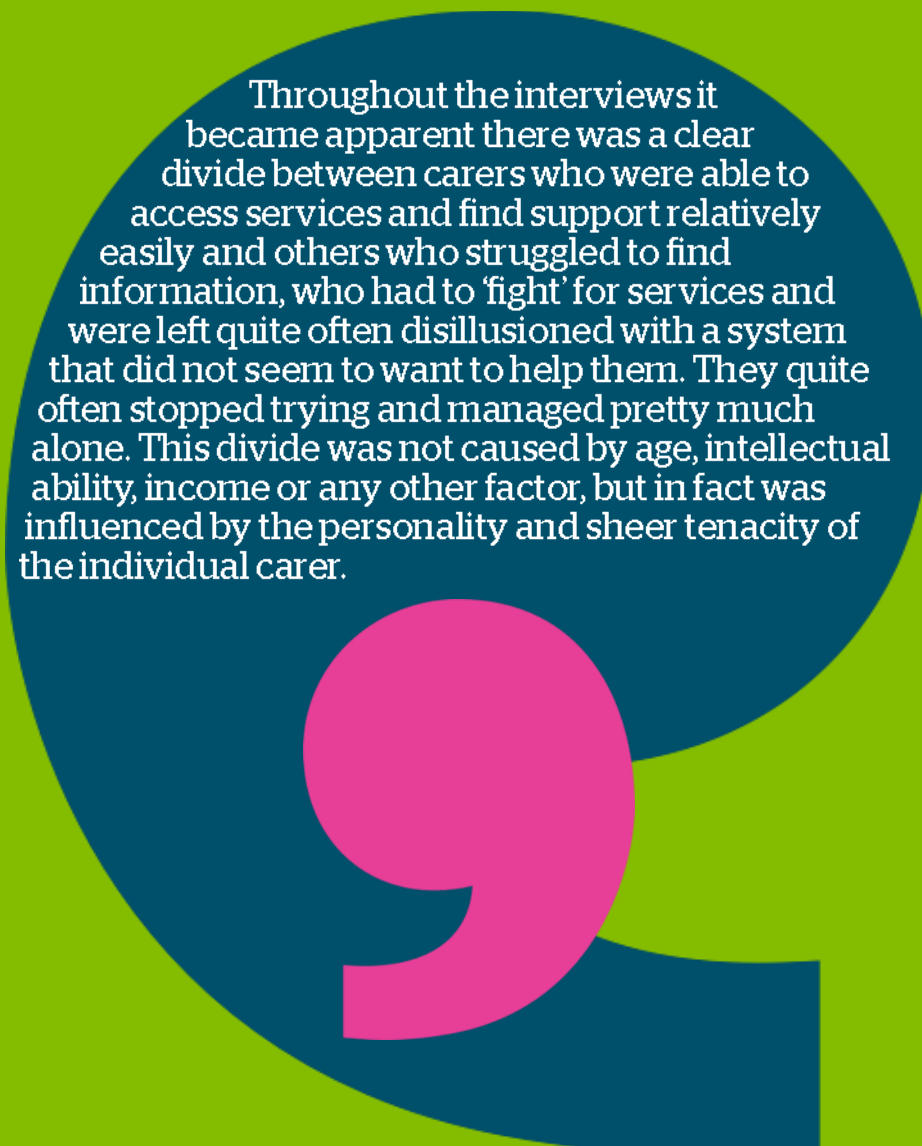
For many the best reward is when they can see their cared for person enjoying themselves.



'I love to see her laugh'

Many carers said that they cannot relax or take full advantage of respite if they feel that the cared for person will not be also having a positive experience. However, they are ready with appreciation of services that recognise the needs of their cared for person and address them fully together with the recognition of their role as a carer.

Accessing Services – linking to communication and assertiveness



Throughout the interviews it became apparent there was a clear divide between carers who were able to access services and find support relatively easily and others who struggled to find information, who had to ‘fight’ for services and were left quite often disillusioned with a system that did not seem to want to help them. They quite often stopped trying and managed pretty much alone. This divide was not caused by age, intellectual ability, income or any other factor, but in fact was influenced by the personality and sheer tenacity of the individual carer.

Peer Support and Mentoring

Much of the above two sections relate to exploring fully the potential of greater peer support and mentoring. During conversations with carers we came across a breadth of knowledge and experience from carers we met. One carer had identified some very effective distraction techniques for her cared for person who had dementia with Lewy bodies, a most distressing condition which can cause frightening hallucinations. Whilst not denying that he was experiencing them she told them to ‘Clear Off’. This enabled her cared for person to relax as although they did not go away, he knew that they were no longer bothering his carer. This was a real skill that needed sharing carer to carer. We met carers who cared for people with similar disabilities, this was especially true of younger people caring for people with physical disabilities, but as they often lived at opposite ends of the Island, they would never meet, yet had so much to learn from each-other, not just practically, but with emotional coping mechanisms too. Another area was that of mental health where carers were frequently embarrassed to share their problems because of the nature of the illness. It is felt that more development is needed in this area, especially with the use of social media and other electronic means.

Experiences of health and social care services:

We asked carers to share their experiences with health and care services.. They often had key messages for professionals in these services.

We have clustered these under different headings

General

- 'Treat me as an individual, a person in my own right'
- 'Respect my role as a Carers and the knowledge that I have'
- 'Support me in my role as a Carer'
- 'Keep me informed and tell me where I can go for help'
- 'Services should work together'
- 'Mental health should be given the same parity of esteem as physical illness'
- 'Be aware of the extreme isolation of Carers of people with mental illnesses'
- 'Unfairness in the system -some get - others don't'
- 'Letters do not arrive - always have to chase.'
- 'Workloads are too great, some people get neglected - this is where systems fail.'

GP

- 'Recognise me as a Carer '
- 'Don't write them off (physical illnesses) just because they have dementia'

Social Care

- '2 hours sitting service is inadequate '
- 'Do not reduce physical activity components of Personal Budgets, they are important for their health benefits'
- 'Cared for people needs meaningful activities during respite care'
- 'Continuity of social care staff, or staff being properly briefed before review visits'
- 'There should be more activities for older men with mental health issues'
- 'Carers services should be more widespread, more diversity in groups and flexible'
- 'Carers Assessment Form'

Hospital

- 'St Marys' is no good with older people - it should be a centre of excellence'

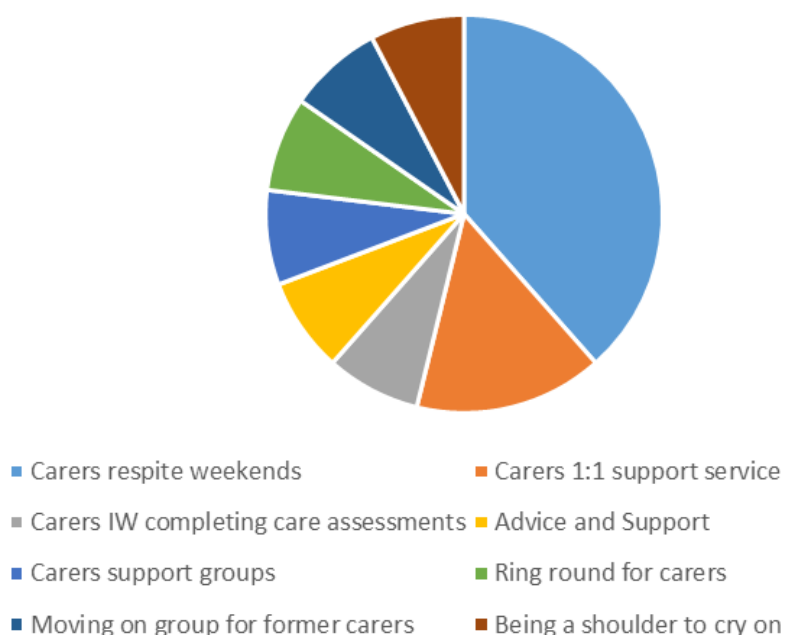
What works well in health and social care services

We then asked Carers what worked well for them. The purpose of this question was to highlight and share good practice, as it is often the approach that makes the difference to how a service is seen to be delivered. Unsurprisingly, given that almost everyone we spoke to had been introduced to us through Carers IW, many named them as the best service within the health and social care sector. However, it was important to hear more about why they rated carers IW so highly. An example is given below;

'Carer was due to attend a respite event, she got very nervous and decided that she couldn't go. She rang the Carers IW office and staff did not just accept apologies, gave reassurance and explored her concerns about attending. This gave her the encouragement and confidence to attend, which she did and she thoroughly enjoyed the event, feeling that she was amongst friends'

It would be easy to assume that carers can be very negative about services available to them, however, during our conversations with them, we found that they very keen to tell us where they experience positive experiences when dealing with services. As anticipated, many mentioned the services of Carers IW. Their comments related to the whole range of service that Carers IW offer. With 5 mentioning the Carers Respite weekends, two stating the Carers 1:1 support service. With others saying that to them it was; Carers IW completing Carers Assessments' with them, Advice and Support, Carers Support Groups, Ring round for Carers, Moving on Group for former Carers and finally being; 'always a shoulder you can cry on'.

Praise for Carers IW Services



However, other service areas and individuals were also highlighted as making a real difference and included; a GP from Esplanade surgery 'a good listening ear', and a GP from Medina Healthcare.

Also:

Northbrooke House- flexible respite

Merrydale residential home - respite care

Motability

Disabled Facilities Grants (DFG)

Continuing Healthcare

Optio voluntary car service - safe transport

Milford Del - 'matching carer and cared for person based on age and interests, so they are more like friends than carer and cared for.'

Memory Service

District and Community nursing teams - 'great care at all times of the day and night, very helpful'

OT and Speech Therapy



What would make your life and those who you care for better?

Our penultimate question asked what would make life better for both carer and cared for person.

One Carer of a person with dementia simply said, 'If this (the dementia) hadn't happened'

For several, having the time to volunteer made all the difference, giving them a sense of self-worth and helping them to maintain their self-esteem. Being able to make a difference within their local community also reduced feelings of isolation and the sense of being part of a team contributed to overall wellbeing.

One carer suggested that having the support of a sensitive male support worker who could work alongside his son to motivate him to do things, would make all the difference. The son (cared for person with a mental health illness) has a lot of assets and showed a huge caring side when his father was dying, but no-one is helping him to realise his potential.

Others said caring responsibilities meant that they could not take up the offer of support from Carers IW, especially the respite weekend.

Another said that it would help if professional stuck to appointment times as 'Carers don't have all the time in the world.'

Finally, one experienced Carer told us; 'Nothing, we are as organised as we can be'

Conclusion

Carers come from all walks of life, they often care for loved ones with a multitude of needs. They give their time, their energy and their commitment to promote the quality of life of the cared for persona and this is done without thought of appreciation or gratitude.



There is currently in excess of 16,000 people on the Island with a caring responsibility and this is likely to rise in the coming years as people live longer but with more long term disabling conditions.

Many carers within our local community will not be accessing crucial carer services which make the huge difference in ensuring that these people can continue in their role as they provide both practical support and vital information and advice. The sheer scale of carers when compared to the capacity of support organisations like Carers Isle of Wight is daunting. Carers IW estimate that they provide targeted support to approximately 100 Carers with another 500 supported through groups, newsletters and ad hoc support. These are impressive figures as there are only three full time members of the team, with others contracted to deliver specific services often on a short term basis. It is patently clear that in order to continue to provide a lifeline to carers, there should be significant investment in carers services. Carers themselves spoke of carers services as a vital provision in ensuring that they could continue in their role and have some life outside of caring. They were aware of the limitations of the service and spoke of 'having had their turn' and that others had greater needs, although they would have welcomed on-going support.

Let us be clear caring is an isolating, lonely role sometimes undertaken by people who are themselves aging with long term conditions. Without exception they had put their own health and emotional needs to one side in order to continue their role. They are a fundamental and vital resource for the Island's health and social care economy. They also provide a valuable insight in how improved delivery of health and social care services can improve the quality of life for both themselves and those that they care for.

The need for services to act quickly can prevent the escalation to crisis point, too often we heard that it was only a crisis that prompted social care services into action and this was usually when a carer could no longer continue in their role. We believe that if services acted more proactively at the first point of contact and if they worked more coherently across services in both the private, statutory and voluntary sector that the majority of these situations could be avoided. This does not necessarily mean a greater cost, many support services in the voluntary sector are cost effective and can be accessed without referral. However, we heard time and again that carers were not signposted to these services from health and social care services. Carers IW report that they are seeing an increasing amount of carers contacting them at crisis points and have found themselves providing what essentially is a social work service without the means and sometimes expertise to do so.

Access to good quality advice and information is also vital, overwhelmingly people told us that they 'didn't know where to start' when trying to access services. It was clear that signposting was not enough, many people had never accessed a service or claimed a benefit before in their lives, they needed more than signposting they needed individual and sensitive support. This is not because of a lack of education or intelligence, it was because it was a new, unique, usually emotionally distressing situation they found themselves in. Services must never forget that whilst an enquiry is an every-day occurrence for them and they may have worked within the 'system' for many years, it is often a cry for help in a completely alien situation for Carers. The role of peer mentoring needs exploring and developing further. We often found that there were similarities in situations, particularly for physical disabilities, where a carer with years of experience could provide invaluable support to those just beginning their caring role. Those who care for people with mental health issues are further isolated as there is still a great deal of shame and stigma attached to mental ill health. Care Navigators working across all localities and with all age groups are potentially another positive step, though as one professional commented; 'We have made the system so complicated, people need Care Navigators'.

Recommendations to the IOW Local Authority:

The review of young carers services and its subsequent strategy should include an in depth consultation of young carers across all age groups. It should also ensure equality of service across age groups and in all settings, including schools.

The recent focus on transition should continue to be a driving force for proactive change.

Flexible training should be made available in communication skills and assertiveness, this should include face to face and on-line training in order to gain the greatest take up from carers.

Consideration should be given to how the current Wightcare carer alert card and the carers register should be combined and link into adult social care recording.

Respite opportunities for younger disabled people should be reviewed and should ensure that they have appropriate and meaningful activities.

Simplify carers assessment forms in line with the new ` Accessible Information Standard ` and provide adequate support in their completion.

In order to minimise the risk of crisis situations occurring, a point of contact should be made available within Local Authority Adult Services to ensure carers can receive appropriate support when they need it.

Recommendations to the IOW Local Authority and the IOW Clinical Commissioning Group:

Peer Support and mentoring, already a priority area of the IW Carers Strategy, should have a greater focus as this has huge potential in empowering carers.

The implementation of systematic registration of carers on both Health and Social Care records to ensure all carers are recognised as such, where this is their wish.

There should be greater recognition and targeted support for carers of people with mental health problems, together with ongoing work around parity of esteem.

There should be clearer pathways and forward planning for people suffering from dementia and their carers.

All Adult Social Care and NHS Mental Health staff to refer carers to Carers IW, so they can learn about what is available to not only themselves but also the people they care for when appropriate.

All Future Mental Health Strategies should make provision to support unpaid carers.

References

2011 Census— www.neighbourhood.statistics.gov.uk

Working together with Carers Strategy—<https://www.iwight.com/Meetings/committees/cabinet/10-12-13/PAPER%20F%20-%20APPENDIX%20A.pdf>

Carers Assessment Form—<https://www.iwight.com/documentlibrary/view/online-carers-assessment>

MS Society—<https://www.mssociety.org.uk/ms-support/for-carers/looking-after-yourself#info>

The State of Caring 2013, Carers UK—<https://www.carersuk.org/for-professionals/policy/policy-library/the-state-of-caring-2013>

Valuing Carers 2011, Carers UK—<http://circle.leeds.ac.uk/files/2012/08/110512-circle-carers-uk-valuing-carers.pdf>

Health and Social Care information Centre 2014/15—<http://www.hscic.gov.uk/catalogue/PUB18423/per-soc-ser-sur-ad-car-eng-2014-15-rpt.pdf>

NHS England 5 year forward view—<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS England Commitment to Carers 2014—<https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

Caring into later life, Carers Uk—<https://www.carersuk.org/for-professionals/policy/policy-library/caring-into-later-life>

IOW Children and Young People Plan 2014-17—<https://www.iwight.com/documentlibrary/view/children-young-people-s-plan-2014-2017>

End of Life Care Strategy—<https://www.iwight.com/Meetings/committees/Health%20and%20Wellbeing%20Board/10-12-15/PAPER%20E.pdf>

Hidden from View, Children Society—http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

Living well with Dementia on the Isle of Wight—http://www.iownhs.uk/Downloads/Policies/Dementia_Strategy_Document.pdf

Isle of Wight Mental Health Strategy—http://www.iownhs.uk/Downloads/Policies/No_Health_Without_Mental_Health_Strategy_Document.pdf

Children and Families Act 2014—<http://www.legislation.gov.uk/>

NICE (LGB14) - <https://www.nice.org.uk/advice/lgb14/chapter/introduction-ukpga/2014/6/contents/enacted>



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