# **Glasgow Carer Partnership**

# Performance Framework Annual Reporting 2016/17

Glasgow City Carers Partnership launched in December 2011 is regarded as a model of good practice in carers support services. We have developed carer pathways through building effective partnerships with carers, carers groups, the voluntary sector and statutory agencies and developing a single point of access.

The partnership has established a universal offer of assessment to carers via the Carer Information Telephone Line, Carers Booklet, including the self-assessment / referral form. All caring situations are assessed by the statutory carers' team for risk of breakdown of the caring role. Information and support services are provided with partners within a whole systems partnership approach as appropriate. All carers are offered a Health Review and an Emergency Plan.

The partnership brings together Glasgow Health and Social Care Partnership, NHS Greater Glasgow & Clyde and the network of voluntary sector carers centres and condition specific organisations who have worked together to re-shape carer services, making best use of available resources to develop a one stop shop approach for carers to access support services.

The aim was to develop a more cohesive partnership approach across the city that avoids duplication and maximises the use of available resources and expertise with equity of provision.

The Carers Reference Group and Voices for Change local and city wide structures ensured that carers were involved as key partners through representation on the Carers Planning & Implementation Group.

This partnership has focused on the development of anticipatory pathways for advice, information, training and support for unpaid carers. The partnership with the NHS allows carers to be identified at the point of diagnosis/onset of condition with primary and acute care services identifying carers and promoting the carer pathway. Anticipatory health and social care approaches aim to support to carers to have the skills and knowledge to support the person they care for to live well with their condition at home and in the community. Preventing breakdown in carer mental and physical health also underpins this anticipatory and preventative approach. Crisis intervention services are also available to support carers where the impact of caring is complex and where the cared for needs are increasing and putting strain on the carer.

This annual performance report evaluation provides evidence of how well the partnership has succeeded in its stated aim to deliver good outcomes for carers through better joined up service provision.

# Glasgow Carer Partnership - Performance Framework Annual Reporting 2016/17

This report provides an overview and analysis of how well the Glasgow Carers Partnership has succeeded in its stated aim to deliver good outcomes for carers through increased partnership working, better joined up service provision and reporting for the period 16/17. The report also provides information

#### Universal Offer of information, advice and support - Carers Information Line (CIL)

South East Carers Centre is responsible for managing the city wide Carers Information Line (CIL) on behalf of the Glasgow Carers Partnership to deliver the universal offer of information and advice to Carers and to promote the self-assessment as the access point to services. It is also how Carers access the city's Carer Privilege Card. The CIL is open to professional staff looking for advice to support Carers. NHSGGC Acute Services promote the CIL with Carers and families.

The CIL has a steady flow of enquiries from both Carers and professionals. During periods where awareness raising activity/publicity took place e.g. Carers Privilege Card Launch, Cinema initiative and Emergency Card Launch numbers of calls increase.

Period	13/14	14/15	15/16	16/17
Nos. of Callers	547	427	340	392
Advice & information	169	177	73	60
Carer Support	143	127	187	152
Self-Assessment Completed	108	96	76	99
Carer Booklets Sent Out	121	105	58	82
Carer Privilege Card	72	47	39	40
Professional Calls	98	122	130	154

Overall the CIL statistical information demonstrates a successful infrastructure to focus on early identification and prevention of crisis with callers being directed to appropriate supports. Figures were thought to be decreasing due to an increasingly more robust referral protocol direct from diagnostic teams however there has been a slight increase this year showing when averaged over three years they may have plateaued around the 400 calls annually.

This is still seen as positive as more Carers are engaged with services earlier.

We are also confident that our statistical returns demonstrate an increasing focus on anticipatory supports with over 73% of new Carers identified in 16/17 receiving support from the Carer Services including information and advice, training, emotional supports and short breaks.

#### **Assessment & Care Management**

Glasgow Carers Partnership introduced the carer self-assessment as the single gateway to support services. Caring situations are assessed by the statutory carer teams for risk of breakdown of the caring role and information and support services are provided with partners within the whole system approach ensuring clear pathways for carers to receive support and achieve good outcomes which can be evidenced through the review process.

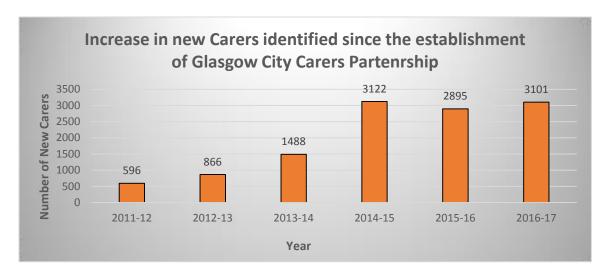
The introduction of a standard set of carer assessment and care management processes, paper work and a recording data set across statutory and voluntary carer services has provided a wealth of comparable information for monitoring and performance purposes. All services also share a common carer outcomes evaluation process for measuring outcomes and these can be routinely reported.

Case studies are provided to evidence good outcomes for carers and evidence of shifting the balance of care.

Pathways for carer Information, Training and Support have been developed for each care group and show year on year increasing numbers of Carers benefiting e.g. increase in Parent Carers of 407% (3,263 Carers) and Dementia Carers of 524% (3,154 Carers) since the start of the partnership.

# **Summary Statistical Analysis**

In 2016-17 there was 3101 carers entering the carer services pathway for information, training and support. Of these 2885 were adult and older Carers and 216 were young people with a caring role. This shows a 380% increase since the partnership was established and a possible plateau of around **3,000 per year**. It should also be noted that the figures since 2014 are recorded with more consistency across the city for more accuracy.



#### Impact of the caring role

The integrated assessment processes allow for Carers to be triaged to access the right levels of support at the right time. As can be seen from the pie chart below the focus on



early identification is being achieved. 73% of Carers supported over 16/17 were able to be supported though carer centre information, advice and anticipatory services. 21% of the Carers were assessed as having moderate to substantial needs and 6% with critical needs and these Carers would be supported by Social Work Carer Teams where the intervention is often an increased package for the cared for and respite for the carer.

There were 180 P1 critical adult caring situations at the point of referral with 571 P2's, 2134 P3's at the end of the year.

# **Referral Pathway**

Our intention is to increase the referrals from primary and acute care over 2017/18 and beyond and targets will be set around this. There is a very slight increase of referrals form Primary Care this year and it is hoped this will be more significant in 17/18 due to the increase in new information workers resource from 1 to 3 in terms of awareness raising and booklet distribution in the middle of the year.

Referral Sources	% 13/14	% 14/15	%15/16	%16/17
Primary Care	18%	17%	14%	15%
Acute	4%	4%	2%	2%
Social Work	26%	23%	26%	36%
Other	53%	56%	58%	46%

The increase in social work referrals may be as a result of new referral protocols with Social Care Direct and a decrease in 'Other' referrals may be as a result of better recording decisions at the start of 16/17.

In addition to the above in 2016/17 there were 602 carers received an Income Max service and there were no recorded complaints to the services during the year.

#### **Carers Outcomes**

The report below is based on Carer Service Evaluation Returns to Carer Centres over the full year 2016/17. 1309 forms were sent to Carers after the carer assessment and services had been put in place. 447 were returned representing an approximate return rate of 34% The indicators below are based on Talking Points carer defined outcomes. During 2016/17 a CF6 e-form has been developed to allow Social Work Carer Teams to be able to record and report on carer outcomes and this will be reportable 2017/18.

National Outcome 6 is defined as "People who provide unpaid care are supported to look after their own health and well-being, including to reduce any negative impact of their caring role on their own health and well-being". The evaluation form provides us with data to reflect the content of National Outcome 6 and Talking Points'.

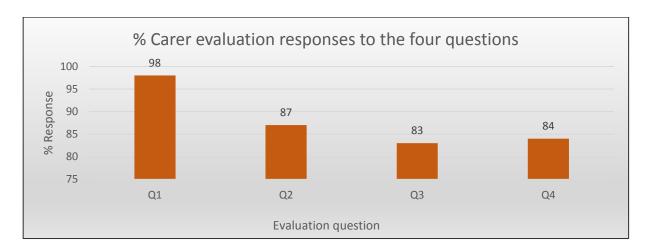
#### **Qualitative Evaluation Questions**

01 -	Did you f	eel valued a	and respected	d by the care	r support worker?
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Q2 - Improved your ability to support the person that you care for?

Q3 - Improved the quality of life of the person you care for?

**Q4 -** Improved your quality of life?



- 98% felt valued by the worker an increase of 1% from last year
- 87% said the support improved their ability to care and increase of 7% on last year
- 83% said the support improved the quality of life of the cared for an increase of 11% on last year
- 84% said the support improved their quality of life an increase of 5% on last year

The increases or decreases in the % evaluation responses from the previous year are marginal and all higher than the % target of 65%

# **Promoting Carer Health & Well Being - Carer Community Nurses**

The carers nursing service was initially developed from North Glasgow CHCP's Keep Well initiative in 2006 were carers were identified as a disadvantaged group who would benefit from a targeted anticipatory care approach.

The recent evaluation of this service looked at the current and future requirements of the service including a review of the nature of the tasks to ensure consistency and equity of service as a result of this review and further developments has resulted in a new Heath Review team that works within the same prioritisation model as the wider Carers Partnership P1 Critical – P3 low.

The team is now made up of three Carers Health Liaison Workers (CHLW) (one per sector at Band 3) and a city wide Carers Community Nurse (part-time Band 5) who is clinical support to the CHLW's and covers P1 situations across the city. This is seen to be an effective dedicated service for carers which is not available from any other source and this new model of delivery will be reviewed in July after Q2.

Indicator	2013/14	2014/15	2015/16	2016/17
Total no of health referrals received	501	533	561	473
Total no of health Referrals carried out	488	535	555	284
No's of follow up visits	91	102	19	16
No's referred to Live link (counselling)	84	102	190	97
No's referred to other agencies	302	323	271	86
No's referred to GP	176	189	232	89
No's of booklets distributed	7431	8839	1828	1353

The Health Review Team are based within the social work carer teams with a remit across each of the 3 areas of the city in partnership with social work and voluntary sector. There are days where the team can be based within the local carer services.

# Training, learning and capacity building

The availability of training and learning opportunities for Carers is critical in building carer confidence and capacity to continue to care and is one of the core services provided via the network of carer services in the city. It also provides important emotional peer support and friendship opportunities for Carers which also increases carer health and well-being. Feedback from Carers educational and training courses are positive.

Many Carers also report an increased knowledge of other services available to them, particularly third sector services and have accessed them via signposting by the statutory and voluntary sector carer services. They reported an increase in knowledge, skills and confidence in coping with their caring role. This in turn can lead to good outcomes and quality of life for both the carer and service user.

The continued investment in the Training Coordinators from CIS to support the carer training agenda locally and city wide to make better use of available resources. These resources include a range of national and local condition specific organisations who provide carer training as part of their remit. Specialist nurses and a range of other health staff also provide training for carers. In Glasgow, Cordia offer free training for Carers via the Carers Privilege Card.

Over 2016/17 881 Carers were referred for and attended attend 88 courses. 54 carers received bespoke moving and handling training and 118 attending a 1:1 appointment for Power of Attorney / Guardianship advice. There were 21 different peer support groups run over the year with 1041 carer places filled over 275 group sessions.

Short breaks/replacement care and transport were provided as required. The courses are as diverse as Caring with Confidence and personal effectiveness, understanding dementia, emergency first aid training, relationship building, understanding autism, managing challenging behavior and a range of other topics provided to meet identified need.

Parent Carers Autism training is also, through evidenced demand, now available in Mandarin for those families identified through close work with the Child Development Centers.

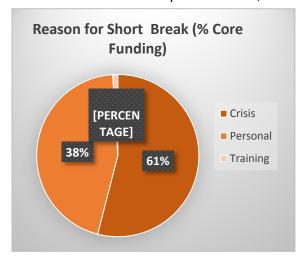
The Training Co-coordinator role has provided significant support in the delivery of training to Carers in line with the care group Carers Pathways.

There is now more direction in how needs are analysed and how the overall training process is coordinated. There remain some variations across sectors and also ambiguities around funding routes, equity of funding and processes.

Fundamental to this review will be the overall review of the core service provision and funding. As it stands, the Training Co-coordinators provide a resource that is not sufficiently available as a component part of core services. Without this resource, training during 2017/18 would likely be significantly compromised.

#### **Short Breaks for Carers**

There was a total of £262,408 spent in 2016/17 providing 17,217 hours of short breaks to 713 distinctive carers to prevent crisis, to allow a carers to attend a personal appointment,



event or to allow carers to attend training. The £263k includes SW core funding and all Integrated Care funding in SWS and Vol. Sector. The access to carer short beaks by duty social workers and wider teams allows effective intervention in situations of crisis. The immediate supports provided assist the carer to continue in their role while preventing an admission to care for the adult.

The Scottish Government 'Time to Live' fund had been accessed for the fifth year. Submitted and managed by South West Carers Service this has provided city wide funding over the last few years evidencing good outcomes through a partnership

approach. In the fifth year of Time to Live 173 grants were give amounting to £45,192 which 233 individual Carers benefited form.

In 2016/17 an additional flexible short breaks initiative was funded through the IJB for more imaginative personalised short breaks where the core short breaks fund above was not directly about replacement care or the most beneficial to carers. Some examples this fund are:

- equipment for a sensory spaces in the house where they can leave their child in a safe environment for a while giving a bit of a break
- spa breaks and associated replacement care where carers would never manage to get away
- a garden shed where a carer can see time out in small periods without replacement care were appropriate

There were 249 adult carers and approximately 122 Young Carers (through groups) benefited from this fund and it provided much needed support in imaginative ways where many time evidencing it less costly than full replacement care agency hours for the same outcome.

Therefore the total Short Break budgets were used to provide positive outcomes for the 1317 carers who received a service in 2016/17 in a flexible personalised way.

#### **Emergency Planning Service**

The Emergency Planning Service was introduced in 2013 as a result of identified need from older learning disability carers who were worried about the future should something happen to them. The Emergency Planning Service was limited to caring roles where the cared for person was over 65 years of age.

The Glasgow Carer Partnership has always worked on the premise that the additional grant funded Emergency Planning Service resource was always viewed as time limited and as such the Service Specification within the Carer Support Services contract from 1st May 2016 included a requirement that all providers would support adult and parent carers to develop emergency plans where required.

Carers services are currently reviewing how best to meet the Emergency Planning requirements of the Carers (Scotland) 2016 Act as well as promoting Anticipatory Carer Plans which would be available to all age groups.

Over the 4 years of the project around 1500 plans were completed with all older carers known to service being identified and being offered the an emergency plan and emergency card.

The emergency plan when agreed with the carer and wider family is flagged on the Social Work Information system with a unique number printed on the Carer Emergency Card which allowing emergency services to access if required. A copy of the plan remains with the carer and can be shared with GP, friends and neighbors as required.

This table highlights the numbers of plans put in place but also the impact that the service has had on carers.

Indicator	13/14	14/15	15/16	2016/17
No's of Emergency Plans (end 12/13 = 70 plans)	348	350	407	378
% carers feeling more secure having plan in place	95%	96%	94%	99%
% cared for feeling more secure having plan in place	87%	84%	85%	80%
% confirmed increased support from family members	58%	69%	68%	69%-
% carers feel supported in their caring role	85%	85%	84%	96%
% reporting reduction in stress	90%	91%	90%	89%-
% referred to legal advice for POA/Guardianship	61%	52%	54%	58%

#### **Carers Privilege Card**

The Glasgow Carers Privilege Card continues to be promoted through the GCC Carers Card website, Carers Information Line and by the carer services and centers across the city. There were a further 1,221 cards distributed to new Carers this year giving a total of **11,314** cards having been issued since the launch in Sept 2013.

This card introduced by Glasgow City Council (GCC) in 2013 provides a range of discounts, including Glasgow Life gym membership, cinema entry, parking, and a range of other services and access to GCC staff benefits.

Adult Carer Case Study 1		
Care Group	Over 65's/Dementia	
Referral Pathway	Carers Support Team	
Carer	Son	
Cared For	Mother	
Priority	P2	

#### Background

Son was referred to us by Social Work Carers Team for joint working. Mother is 89 and has dementia and is a Diabetic Type 1, she also has really poor balance and is at risk of falls. Son is a diabetic Type 2 and has Mental ill health. Mum's dementia is having a detrimental effect on son's mental ill health. Mum is very repetitive and Son is finding this difficult. Son's feet are also very painful through the diabetes and his eyesight is beginning to fail. When I carried out the home visit Son was due to go on holiday for 10 days.

When Son was referred, SW Carers team had already taken some steps to provide respite for Son when he was going to be away- Home Care Service daily to see mum for the period of son's holiday, liaising with the appointed Social Worker. Son was informed of the benefits of training. Son wasn't convinced that this was a good idea, he mentioned poor literacy skills, and this was identified as a possible barrier to training. Son feels mum being repetitive (repeating herself constantly because of her short term memory loss) causes high levels of stress.

Son worries about anything happening to mum or anything happening to him and the caring role breaking down.

# Output: (can list core service/s here e.g. Info & Advice, Short Break)

- Completed Carers Support Plan
- Telecare Referral
- Dementia training referral One on One home visit basis from dementia condition specific organisation
- · Referral to condition specific mental health service -
- Emergency Plan Referral
- Personalised Short Break Application
- Emergency Planning Referral

# Outcomes:

- Reduced stress and anxiety for carer and service user
- Improved health and wellbeing
- Reduction in isolation for carer and service user
- Increased access to social and recreational opportunities
- Increased ability to manage caring role.

#### **Impact**

Joint working and good communication between agencies meant appropriate supports were accessed quickly. Telecare was installed quickly, before an impending holiday, which along with Short Breaks, allowed the cared for to remain at home during the Carer's holiday, and providing a safe alternative to traditional building based respite. Group training was proving a barrier to access for the Carer, and the flexible one to one service means the family relationship will benefit from this going ahead. Carer now has dedicated support with improving his own mental health, and has the opportunity to take time and look after his own physical health, assisting him to continue caring for as long as he wishes.

# Reflective learning from the case that could inform service development.

Joint working can be extremely effective when communication is good, avoiding duplication of work. A telecare package which was in place in two days, and the same service offering to also fit a key safe, showed joint working that allowed a Carer to go on holiday, with home based respite and support which gave piece of mind and reduced stress for both the Carer and Cared for person.

This case also evidences the importance of considering the needs of service user and the carer while completing the assessment. This holistic approach considers best outcomes for both parties.

SWS Carer Team – Case Study 2	
Care Group	Older People – Dementia
Referral Pathway	Primary care – Memory Clinic
Carer	A
Cared For	В
Priority	P2

#### **Background**

Mr A is a 53 year old male and was referred to the SWS Carers Team when his mother Ms B 88 was attending the memory Clinic. The initial outcomes identified were regarding supporting the carer to manage caring and balance work commitments. Mr A was requesting residential respite for his mother Ms B.

Mr A's father died 5 years previously and he has a partner who he intended to travel with on a 3 x weeks holiday. Ms B has a package of care from Cordia, attends a Day Carer service which she self-funds and the home has been adapted to meet Ms B's carer requirements.

Mr A works part time, and was assessed as being priority 2 carer as he has limited support networks in Glasgow. If he were unable to provide the level of support for his mother she would require a significant package of support to remain in the community. Mr A was initially requesting residential respite for three weeks to allow him to have a complete break from caring.

# Output: (can list core service/s here e.g. Info & Advice, Short Break)

Carers Support Plan completed with a focus on the outcomes important to Mr A and Ms B. Short breaks arranged to cover three weeks' vacation period – 20 hours £304.00 Dementia awareness training arranged for Mr A and his partner.

Emergency Plan Completed by Partnership Worker. [ Delay in providing due to vacant post]

Mr A also downloaded Anticipatory Carer Plan and completed himself Mr A declined health review as he frequently sees GP due to type 2 diabetes. POA was already completed.

# Outcomes:

Mr A reconsidered residential care for his mother as it was likely to cause upset and distress for his mother due to dementia and changed environment. Ms B was recently diagnosed with dementia and still has the ability to manager her care and medications with prompts and some practical support. Mr A stated that his mother was absolutely delighted with the support received from local home care provider. Mr A is aware to contact SWS Carer Team or Carer Centre if and when he needs support in his caring role.

Mr A provided the following feedback in the service evaluation form.

'I found it useful to have someone to ask for help at short notice. I can get coverage in place to help my mum and allow me to step away from my caring role. I found it helpful that my mum can be in her own home and can be supported.'

#### **Impact**

At initial point of referral, Mr A could have been considered as P3 anticipatory intervention as his mother was recently diagnosed and all were coping with support provided. Mr A was also willing and able to continue caring for his mother. However, Mr A had very limited support and the carer plan would have collapsed if he were unavailable, and he also his own health issues [type 2 diabetes] The dementia diagnosis suggest that the caring role was likely to increase in future and while both SWS Carer Team and Carer Centre supported Mr A, he was assessed as a P2.

While Mr A initially requested residential respite, a package of personalised short breaks in the family home was able to benefit Mr A and Ms B and caused minimal disruption to both parties. The £304 short break support was provided with no charge to the carer or service user and a cost effective alternative to three weeks in a residential environment.

Mr A clearly evidenced his ability to plan for his holiday and he downloaded and completed an anticipatory care plan as well as contacting relatives to make them aware of plans should their support be required.

Mr A's case would be considered as a positive example of partnership working. Services working together to identify when someone becomes a carer at point of diagnosis and Carer Centre and SWS Carer Team working together to meet carer outcomes.

Mr A is also an example of enabling and empowering a carer to be fully involved in care planning and completing tasks he was able to do for himself. The carers Support Plan was able to positively acknowledge his caring role to date, and consider current and future options to make support available that met both his mother and his outcomes for the future.

Due to Mr A's significant caring role, his case will remain open on a monitor and review basis by SWS Carer worker.

Adult Carer Case Study 4	
Care Group	Parent Carer
Referral Pathway	Specialist Nurse in Primary Care
Carer	Mum
Cared For	Son C
Priority	P3

#### Background

M has two children. Her daughter is 3yrs old, and her son C, is 5yrs and been diagnosed with two long term conditions. Due to C's bowel problems, he needs to be encouraged to use the toilet and he can soil himself through the day. Mother must wash C in the bath and change his clothing and bedding. Mother administers his complex round of medication daily and attends all hospital appointments with him. The school now have a supply of clothes and cleaning items for C to avoid him being taken out of school when he has an accident. C presents with hyper-active behaviour and needs a strict routine as changes can agitate and upset him.

Mother's current property is causing some stress for the family, as there is only one bathroom and no shower, and C can become very soiled due to continence issues. This happens regularly and without warning. Mother has a good relationship with her Parent who will take C and his sister overnight. C's parents are separated and his dad visits him daily and is also a good support to the family.

# Output: (can list core service/s here e.g. Info & Advice, Short Break)

- Completed Carers Assessment
- Information & Advice OT Referral
- **Money Matters** Application to Caravan Project for reduced cost holiday £200, normally £600
- **Short Break Service** Personalised Short Break (PSB) Budget to assist with the cost of accessing the Caravan Holiday £200

#### Outcomes:

Access to practical support at home which will enabled Mother to manage her caring role better and improve the quality of life for her son C and his siblings. Mother has been enabled to reduce her stress levels and her isolation and increased her breaks in her caring role.

#### **Impact**

Occupational Therapy visited mother within a week of my request, carried out an assessment and is now in the process of installing the electric shower. This will make a huge difference to mother and to C, especially in the middle of the night if C needs to changed and washed quickly. The OT is also going to work with mother's Housing Organisation to find more appropriate accommodation for this young family and I have provided a letter of support to present to her Housing Officer.

The Personalised Short Breaks funds have allowed a first family holiday. C's grandmother will accompany them to a Caravan and will be on hand to help, giving mother more time to spend with her daughter, who mother feels gets left out a lot is she is having to support C.

Mother will be more able now to ask for the support she needs as C grows and develops. She wasn't aware that organisations like ours were there and didn't realise that the social work teams and Occupational Therapy were there to help, or be so accessible to her. This has been a very positive experience for CM and she knows that she can contact carer service at any time in the future.

In the longer term, supporting C's mother may prevent the daughter having to take on a young carer role for their sibling.

# Reflective learning from the case that could inform service development.

- Holistic assessment can lead to positive outcomes as a result of joint working from different agencies in this instance the OT will install the shower in the meantime but also liaising with Housing Officer to find more appropriate accommodation for the family
- Sometimes it's the simple things that can have the most positive impact for families. This young family are so excited about their upcoming caravan holiday where they can just 'be' together and make new memories, as they have never before had the opportunity, enabling the family to have experiences that other's may take as routine.

#### Case Study 5

# **Background**

Young carer "A" was re referred from education. "A" is the youngest of three children and cares for mum who has mental health problems, a severe physical impairment and obesity and as a result of all these things is housebound. In addition to A there are 2 adult carers; an older sister and grandmother who provide support.

The young carer has been known to the Carers Centre for eight years and has had to contend with personal tragedy when her father committed suicide. Initially supports were provided on a 1:1 basis with referral to specialist child bereavement support services. "A" was very reluctant to speak to her peer group and had few friends in primary school. "A" has attended focussed activities including wellbeing programmes such as cooking and first aid. Not only did this help "A" achieve by boosting her learning and confidence, but has been positive in addressing her own weight, general, physical and mental health issues. Having contact with other young carers her own age supported her transition from Primary to Secondary school and helped her make friends.

- "A" has also been signposted to mainstream youth services and attends mainstream youth service.
- "A" approached me during an outreach session in her school supported by her pastoral care teacher.
- "A" was hoping to leave school at 16 and go to college but said mum saw this as an opportunity to have a built in carer. "A" goes to hospital appointments with mum and collects prescriptions on a regular basis. "A" said mum gets lonely during the day and she also worried about her while she was at school as she was subject to falling. "A" said she rarely goes out at night now as mum wants her at home to keep her company. "A" said she wanted to go to college to continue her studies; she felt she had a lot of the necessary skills and qualities due to her personal experiences at home.
- For "A" to be successful in her application for college to do Social Care she required to achieve specific grades in English, Maths and Science and 2 references; educational and character. However the pressure of "A's" caring role and a breakdown in her relationship with her mum was beginning to have an effect on her school work at such a crucial time and her pastoral care teacher was unsure if this could be achieved due to attendance and performance issues.

#### **Actions**

I felt the best option was to work collaboratively with the adult carers support worker to see if we could again alleviate the young carer's role. A joint home visit was carried out and a review of the support required by the cared for and the support provided by the adult carers was discussed. It appeared an assumption had been made that the young carer would automatically take on the caring role on leaving school. "A" was supported to share her aspirations with her mum, sister and gran highlighting how this would also improve the families financial situation as she was eligible for grant support.

#### **Outcomes**

"A" is accessing supported study at local Library to help exam preparation, class teachers are providing additional study aids. This will help her receive support and guidance out with the home environment in addition to her school work increasing her learning opportunities and achievements in accordance with the SHANARRI indicators.

"A" was supported to apply for college and asked the Carers Centre manager for a reference for which she was ultimately successful.

An OT referral review has been requested as mums mobility has deteriorated. "A's" gran and older sister have stepped up to take on more responsibility in particular responding when mum is unwell to reduce "days off" school. "A's" gran and older sister now help to take turns in going to hospital appointments with mum and a new prescription delivery service is now in place for mum. This has made "A's" life easier and made her family home a more nurturing environment to live and grow with a positive relationship with her mum.

#### Case Study 6 Ms B - Young Carer

Ms B was referred to Carer Services as a 12 year old Young Carer for her 34 year old mother Mrs A. At the time of referral Mrs A had been diagnosed with MS for approximately 5 x years. Ms B had a younger brother Master C who was 9 years of age. There were no extended family to offer support in times of crisis. SWS Carer Team became involved following Mrs A's emergency admission to hospital. Ambulance was called and Mrs A received emergency medical treatment in the flat. At that time, Mrs A's MS attacked her eyesight, heart muscles and mobility. Mrs A lived in a first floor flat. When Mrs A was in hospital the children had to stay with a family friend and were unable to visit Mrs A which further increased their anxieties.

SWS Carer Team Project worker visited Mrs A with Young Carer worker from Carer Centre. Mrs A's mobility was limited and she couldn't walk down stairs. She had started using crutches to get around, but wasn't able to leave her flat. Mrs A had to wear sunglasses as she had 'stabbing' pains in her eyes and couldn't cope with bright light. Mrs A was unable to escort the children to school and relied on them for shopping, helping out round the house. Crisis short breaks were put in place to escort the children to school and support Mrs A with personal care and housework. School were made aware of situation. The focus of intervention was to alleviate the role for young carers, reduce anxieties for children and support Mrs A in her role as parent. Mrs A described the workers providing support at home as 'Absolutely amazing' and said it was the best support she had ever had. Service was funded through Carer Team budget at no cost to Mrs A. Mrs A was also supported to apply for housing more suited to her care needs.

SWS Young Carer worker informed Children's Services of situation and made arrangements for children to access respite if Mrs A was admitted to hospital. Respite provider would facilitate hospital visits to reduce the children's concerns.

Young carer worker met with both children and made a referral to Toffee Club for Master C and Outward Bound activities group for Miss B.

Mrs A's condition continued to deteriorate and medication was further complicating the situation as it was making her drowsy and confused. Mrs A was also struggling with coming to terms with her diagnosis. Mrs A accepted referral to specialist MS project and for additional support with her own mental health.

Mrs A was supported to apply for Self–Directed Support in June 2012. YC assessment was completed by SWS as part of budget allocation process. Mrs A received a budget of £19,226. The Budget covers 31.5 hours per week normally, increasing by a further 21.5 hours per week during school holidays, Mrs A now employs a Personal Assistant to deliver the personalised support she requires. Mrs A has been rehoused in a semi-detached house which has been adapted to meet her physical care needs. Mrs A has an allocated care manager.

Mrs A's condition will always have an impact on her children which can never be fully alleviated. However, the support that has been provided to Mrs A has given her more choice about the supports she receives. The NE Carer Services focus of supports for Ms B and Master C has consistently been to alleviate the caring role and allow them to be children first and foremost.

Case Study 7	
Care Group	Older People
Referral	Social work duty re cared for
Pathway	SWS
Carer	J1
Cared For	J2
Priority	P2
Dookaraund	

Background

Carer role / history / issue

J1 is married to J2. They have been married for 53 years. The couple worked on fairgrounds and after selling the business 15 years ago, they retired.

They have a daughter and that lives next door and a son that also lives locally. They have four grandchildren under 11 years of age.

Approximately three years ago J2 was having recurring headaches and went to the GP. The GP identified that he had suffered a stroke and he was also diagnosed with dementia. He also has a diagnosis of rheumatoid arthritis which significantly affects his hands and knees. He walked with the aid of a walking stick.

J2 had been helping to take his grandchildren to school but he had attempted to walk out in front of a car and the family are now very aware that he needs support and supervision at all times. He used to be left with the grandchildren after school when they were doing homework. This allowed J1 to have some time out to go shopping with her daughter. However this was stopped after J2 became agitated and threw a cushion at his grandson for being cheeky. This type of behaviour was not normal for him and the family were doing their best to prevent this from happening again.

The couple lived in a gated community and J2 could walk around without being able to leave the area.

J2 was aware that he had a memory problem but was struggling to come to terms with how the condition affected him.

He was refusing to take medication and had a broken sleep pattern. He would stay up till 1am and get up at 5am and go for a shower.

J1 was not getting enough sleep and was finding it more difficult to have time away from caring and ensuring that J2 was safe. J1 was very guarded of their financial and personal business and distrusting of formal services.

# Output: (can list core service/s here e.g. Info & Advice, Short Break)

Interventions arranged and reason

A carer's assessment and health review were completed. Informal reviews of support plan were undertaken 3 x monthly. Information was shared with CPN at memory clinic. In the latter stages a referral was made to Social Care Direct for Shared Needs Assessment in anticipation of requirement for long term residential care.

A referral was made for an emergency plan.

A referral was made for dementia awareness training.

They were provided with information in regards to POA however they chose not to pursue this.

OPPD duty organised respite for a week partially funded by J1.

Telecare was refused.

Short breaks were provided for 2 hours every Wednesday to allow J2 to go for a walk and to allow J1 some time out with caring.

#### Outcomes:

The short break input wasn't perceived by the Carer's Support team to be alleviating the stress upon J1 and improving her quality of life. She continued to refuse Day Care or any services which would involve workers going into the static caravan on a regular basis, as is a cultural norm aspect and workers respected this and her right to self-determination. However J1 was able to focus on aspects such as her own health and gradually stopped smoking.

As J2's illness deteriorated, J1 was getting even less sleep as J2 began to reverse daytime patterns to night time and she eventually accepted an increase in the short breaks service to 2 hours, 3 times a week. For an additional four months this allowed J1 to spend time with her daughter without worrying about her husband, attend to her own clinic appointments e.g. for a podiatry issue and to carry out tasks related to managing her home. This was intended to improve quality of life and support her in the caring role.

Throughout there was ongoing contact between the primary worker and J1, twice with duty OPPD as gradually J1 reluctantly accepted that for her husband's safety and her own well-being till J2 required residential care.

# **Impact**

For more than two years, J1 was assisted to safely maintain the care of her husband in keeping with culturally accepted norms for travellers. She did not feel that she required respite or assistance with personal care. She could have requested long-term care far earlier that she did however with what she perceived as the appropriate supports her husband was cared for at home for as long as possible.

# Reflective learning from the case that could inform service development.

By implementing an outcome focussed support plan where respecting the needs of the carer, even when the primary worker felt that caring role was at times overwhelming, resulted in a level of trust between the carer and social work carer team. This ultimately meant that when eventually J2 could not live safely without full time care out with the family, J1 had developed a working relationship which permitted positive interaction and she was able to relinquish her caring role in the community with dignity. Due to the Carer Team involvement and preparations, J2 was moved into a residential care home as an emergency admission. At the family's request they facilitated J2 admission as it was important for them to do this as a family.

#### Case study 8.

L (71 yrs.) is carer to her mum, M (92 yrs.), who has several ongoing age-related physical difficulties and other health issues; Diabetes, Angina, Arthritis, Irregular Heartbeat, Hearing Loss, Stroke, Poor Mobility. She is frail but determined to maintain as much independence as possible.

M lives in Sheltered Housing, with the support of a Warden during office hours. However, M does not receive practical support from the Warden, instead depending on daily care from L. L supports her mum by doing her shopping, cleaning her flat, advocating on her behalf, overseeing her medication and providing personal care on the occasions that M is less physically able to do so independently.

L has always had anxiety around what would happen if she herself became unavailable. Whilst she has a supportive family, she had never formally broached this subject and wasn't sure how to organise the relevant information needed for her family to provide the best support for M.

L was informed of the service by the Community Carers Nurse and agreed to a referral to the Emergency Planning Worker.

L had not been aware that such a service exists and was immediately reassured to know she would be supported all the way from gathering the relevant information to sharing the plan with Social Work. She felt particularly relieved to have a Carers Emergency Card issued in order to action the plan, if necessary.

Once a copy of the plan was sent to her she then had a document which was helpful in facilitating discussion with her family regarding their potential ability and willingness to help. All family members agreed that they would work together to provide replacement care if L were ever to become unavailable, putting L's mind at rest in the knowledge that not only were they willing to do so, they now had all the information necessary in order to provide the tailored care that M needs.

# Case Study 9

#### Background

Mrs. M is a member of one of our peer support groups. She has cared for her husband for several years as he has dementia. Recently Mr. M's condition started deteriorating rapidly and Mrs. M was finding this very hard to deal with as were the rest of the family.

Consequentially, Mrs. M found the only place she could talk about her situation was within the group. Slowly she was able to discuss her fears around her ability to look after her husband and the inevitability of him going in to full time residential care and the guilt she felt about this.

The group all offered advice and support, an empathetic ear and shared their own experience which Mrs. M found invaluable. Whilst the worker was able to monitor the situation and respond with interventions where appropriate. She says that she "has found strength and courage amongst her peers" and that they have "helped her maintain her sanity on more than one occasion". She also reports that she feels that she is now in a position to offer support to others and is happy to share her own experience.

Mrs. M has also developed a friendship with one of the other woman in the group and they often contact one another through text to check in on each other and offer support out with group times.

#### Output: (can list core service/s here e.g. Info & Advice, Short Break)

- 1. Information & Advice
- 2. Emotional Support
- 3. Personal Development & Wellbeing
- 4. Money Matters (advice around paying for care homes)

#### Outcomes:

- 1. Carer felt better informed
- 2. Carer felt supported
- 3. Carer had a stronger sense of wellbeing
- 4. Carer feels less isolated
- 5. Carer felt less stressed concerning money

# **Impact**

- Carer felt better informed and reported she is more likely to engage with Health & SWS. Mrs. M is no longer afraid to open up to the professionals involved in her husband's life about how she really feels. This has built Mrs. M's confidence in both these services and given the professionals involved a greater insight into the situation.
- Carer felt supported emotionally by centre staff and her peers both offering a different kind of support, therefore, covering all areas. This has allowed Mrs. M to come to terms with her situation and to except that her best id good enough. This has helped reduce Mrs. M's stress & anxiety.
- Through the discussions within the group the carer felt that she was discovering things about herself, her feelings and her situation. Furthermore, that she was gaining the skills, tools and techniques to deal with her emotions. This she has reported "keeps her sane", therefore, helps her maintain a sense of wellbeing.
- Care felt well informed and less anxious about money after advice on what contributions she will be required to pay for husband's care.

Mrs. M feels that the support group has been of great benefit to her emotionally and socially. She feels it has offered her a safe and supportive place to explore her feelings and her options without fear of judgment. She often talks about how dementia makes people stay away and how she has lost contact with most of her friends. She says that the group have helped her feel that she is not alone any longer and that she is delighted to have made new friends (that understand and except her situation) and that she hopes one day to pass on her experience to help others.

# Reflective learning from the case that could inform service development.

I have given this case a great deal of thought as peer support can be very difficult to measure, monitor, evaluate and of course evidence. I have no doubt that Mrs. M would have muddled through this situation without the support of the group. However, I can't say with certainty that her relationship with her husband, her family or her health would have been intact.

It was clear to see that Mrs. M was very stressed and had a great deal of anxiety. This was manifesting in both physical and mental ill health. Being given the space and time to examine her thoughts, feelings and behaviours helped Mrs. M put things, that she has gotten way out of perspective, back into perspective.

It enabled her to understand herself more clearly and gave her the opportunity to change the parts of her behaviour that she was unhappy with. All of this feed into her own wellbeing and the understanding that she was the person responsible for her own health.

All of this lead to her taking steps to look after herself as well as her husband and her family. Mrs. M still faces challenges every day but she knows that she has a place to take them know and that she has the strength to deal with them.