

**Angus Carers Association** is an organisation established by carers, for carers. The Association was established in October 1996 and became part of the Royal Princess Trust for Carers network in November 1997, then becoming known as “Angus Carers Centre”

The Centre is an independent organisation with charitable status and is managed by Angus Carers Association. It became a company limited by guarantee in October 2000. The Centre continues to grow and currently (2013) there are around 1900 adult carers and 220 young carers registered with the centre.

### **Vision Statement**

Our vision is that all carers in Angus will receive appropriate information and support to enable them to feel valued and confident in their caring situation and to develop their own potential.

### **Mission Statement**

Our mission at Angus Carers Center is to improve the quality of life for all carers in Angus.

To do this we:

-  Provide an information and advice service.
-  Offer support to carers at an emotional, practical and social level.
-  Join with carers in becoming actively involved in consultative and planning processes.

**This response is based on 197 postal surveys returned by 188 adult and 9 former carers during March and April 2014. In this response the outcome of the postal survey will be reflected by provided the ‘score’ of the collated responses. So if 86 carers agreed and 89 disagreed then this would be expressed as (86/89).**

**19 carers were also involved in focus groups and further discussion at local events. The outcome of these discussions also informed this response.**

## **Carers Assessments / Carers Support Plans (183/19)**

In relation to the government's proposals on carers' assessments our position is:

- Carers support the name change from Carers Assessments to Carers Support Plan as long as this reflects a change in practice as well. Some wanted it to be called a Support & Action to reinforce this point. The overwhelming view of respondents supported the belief that this more accurately reflects their purpose - which should be to plan what support can be provided to help the carer manage their caring role and have a life outside caring.

### **Carers Views:**

- *Yes – because instead of feeling judged they will feel supported and encouraged to express their worries and fears*
- *Doesn't matter what it is called if it gets done. More emphasis should concentrate on completion*
- *It is important that cares have this and it is acted on and followed up*
- *Yes – it indicates there may be "a more positive" outcome to any interviews etc*
- *This makes it feel like support and not just finding put facts*

### **Removal of regular and substantial test**

- We support the removal of the regular and substantial test (187 /8) and the proposal to extend the Carer Support Plan to all carers as it was felt that anyone who identified themselves as a carer should be entitled to access support. The view was that it is the impact of the caring on the individual rather than the perceived 'amount of caring' they do. The local authority should have a duty to provide all identified/self identifying carers with a support plan. We believe that this will enable carers to access information and support at an earlier stage, preventing crisis and greater cost at a later stage. However, it is vital to ensure that to correspond to intend increase in take-up, local authorities and local carer and other community support services to which carers are signposted are sufficiently resourced to respond.
- We welcome an improved approach to legislate for local authorities to have a process for informing carers of the time it will take until they receive a Carers Support Plan. However, we are unsure that this will solve the current situation where carers can wait many months (indeed years) for their Carers Assessment. Whilst we recognise that there are challenges in setting maximum waiting times, not least that it may become a standard waiting time, we believe that there should be some consideration of a reasonable timescale reflecting the targets already in place for 'the supported person' to ensure that carers do not reach crisis point before they receive support.
- The focus groups agreed with the view that the carers assessment should be separated from the assessment of the cared for person, so that a carer can access an assessment even if the person they care for is not in receipt of any

services as the impact on the carer can still limit their life out with caring. However (144/49) respondents in the postal survey felt that the requirement for the cared for person to be in receipt of local authority services should still be a part of the eligibility framework as it was recognised that resources are finite and this could be an indicator of priority. It was felt to be important to ensure that each carer plan was personalised and allow for changes in the health of the carer or cared for to be taking into account when a carers plan was requested or reviewed.

- We support the option to devolve the process for undertaking Carers Support Plans to the third sector. However, our position is that there needs to be an understanding that the duty still sits with the local authority and there must be a clear process for picking up on needs identified through the assessment. In terms of best practice this should include identified workers from the local authority linking with the third sector organisation. Angus Carers Centre, as partner in the Self Directed Support Implementation Team is developing a Resource Allocation System with Angus Council which will identify any financial support the carer will be entitled to; to purchase services/activities' which will support them in their caring role. It will be important for the local authority to continue to have responsibility for the outcome of the RAS to ensure the Carers Centre can continue to have an independent advocacy role for each carer.

In addition:

- The review process should be clearly outlined in guidance. The carer should be offered the opportunity for a yearly review, as a minimum; however they should not be obliged to take this up. Otherwise carers should be able to trigger a review at any point to take account of changed circumstances.
- Timescale – There should be a defined timescale for Local Authorities to undertake an assessment and also to provide services that carers are eligible for.

### Carers Views

- Agree if this is a genuine effort to identify and provide support for carer
- Is there any point as the term 'support' suggests there will be 'support', but in reality, there is very little
- Having undergone lots of assessments, me and my wife, the last thing I would want to be involved in with is any more assessments!
- The whole ethos should be about supporting people can be reticent about 'assessment' as they don't know whether this is a financial or about their ability/capability to provide care.
- It removes the notion of being examined to determine one's suitability
- Should be changed to carer support AND ACTION Plan
- If the carers assessment are widely available, prefer 'plan' to be flexible i.e. not rigid.
- Providing that by changing the name does not mean a downgrading of services

- ✿ It's only a title – the context will still be similar.

## Information and Advice

In relation to the government's proposals on Information and Advice our position is:

- We support the proposal to place a duty on LAs to establish and maintain an information service. However we have concerns that Local Authorities may try to establish their own services, rather than resourcing existing carer support services. Furthermore it is essential that carer information and advice services are based **locally** and also take account of the needs of more isolated carers. Our position is that there needs to be a quality support framework for carer information services and carers must play a central role in deciding who provides the information service in their area, taking account of existing services. 194 carers felt that the local advice and information should be developed by the local Carers Centre.

## Carers Views

- ✿ *We are fortunate in Angus to have Angus carers Centre for without them there is no central point for the provision of information*
- ✿ *Of course, but this does not happen. If all carers were aware of and accessed these it would cost too much so it is kept quiet*
- ✿ *A lot of carers no knowledge or input. Don't find time and nobody to tell.*
- ✿ *There has to be a consistent standard and the best proactive for advice in my opinion the carers centre*
- ✿ *How otherwise does a carer get the knowledge or detail of what carers support is available*
- ✿ *This is very important as presently this doesn't happen and many miss out on benefits*
- ✿ *Because ultimately the carers health will impact on local services*
- ✿ *I have spent years caring and only getting some assistance no due to the doctor making an appointment for me with a carer from the centre*
- ✿ *It should be a legislative duty*
- ✿ *Until I became a carers was unaware of anything to do with being a carer and it was difficult to get proper information*
- ✿ *Should be a voluntary organisation then the carer will come first no conflict of interests*
- ✿ *That would be great – recognition and support*
- ✿ *Yes – providing it does not become target based*
- ✿ *Yes – in my opinion there can be a tendency to keep the carer 'out of the picture' which is quite wrong*
- ✿ *They should make use of existing local services*
- ✿ *Very much so – I had a lot of finding out to do for myself*
- ✿ *In a culture poor in community spirit, vital to provide*
- ✿ *Organised structures of support – and outreach*

In relation to the proposal to repeal the requirement for Health Boards to produce a Carer Information Strategy. 138 carers indicated that the CIS should be kept to continue a responsibility by the health board in identifying, informing and supporting carers, including directing resources to carer support as a continuation of CIS funding. The mechanisms for directing resources to carer support need to be nationally agreed and embedded within the new integrated partnerships

## Carers Views

- ✿ How to get out and wash your hands of responsibility
- ✿ No – health boards are spread too thin already financially, local support groups are invaluable

## The Duty to Support Carers and Provide and Promote Short Breaks

In relation to the government's proposals on support for carers, including short breaks our position is:

- 165 carers support the proposal to introduce a duty on local authorities to provide support to carers and to provide and promote short breaks, according to an eligibility framework. They also believe that the discretionary power to support carers who do not meet eligibility criteria should be retained. We believe that this approach will result in greater consistency in the provision of support and services to carers and will help to protect carers' health and wellbeing. It should also act as a catalyst to encourage additional investment in carer support services, including short breaks, helping to address gaps in services and the current pressure on available provision

In relation to the development of an eligibility framework 18 carers said this was essential whilst a further 20 said this would be helpful. 10 thought they would be difficult to create but that they would be helpful.

- Eligibility criteria must be co-produced by carers and must be specific to the needs of carers, rather being adapted from existing eligibility criteria for other care groups.
- Eligibility criteria should be produced nationally to avoid further inconsistency in relation to the provision of services and support to carers.
- The eligibility criteria must be linked to the needs of the cared- for person, but this should not be the only criteria determining a carer's eligibility. Additional factors must be considered, such as carers' health, employment status, additional responsibilities outside the caring role, life outside caring etc.
- Eligibility criteria must have a preventative aspect to it.

In addition, our position is that the duty to support must have resources attached to it for it to be successfully implemented.

## Carers Views

- ✿ Yes - For all carers – working, not working, over 65
- ✿ I think both the carer and the person they care for should receive this!

- ✿ Yes – less stressful
- ✿ Respite should continue
- ✿ Keep us going as we save them money by not having the person go into a care home
- ✿ If that includes the person they care for

## Stages and Transitions

In relation to the government's proposals on stages and transitions our position is

- 176 Carers said guidance should be issued on the Carer Support Plan that includes guidance on managing stages of caring. They also believe that young carers who are likely to become adult carers should have a Carer Support Plan, and that this should be carried out well in advance of the young person reaching the age of 18 so that the transition is as smooth as possible.

## Carers Views

- ✿ *Carers should be looked after as well as the person who provides the care*
- ✿ *There are many different levels of caring - hard for outsiders to believe the maximum toll this can take*
  
- ✿ *All carers should have a senior care manager to contact at any time*
- ✿ *Yes because when the person gets worse more help may be needed*
- ✿ *The needs of the carer are paramount to enable them to keep going*
- ✿ *Circumstances change - level of care will change*
- ✿ *Local authorities should get Government support and funding"*
- ✿ *Each situation should be reviewed with an open mind approach*

## Carers as Equal Partners

In relation to the government's proposals on carer involvement in care planning our position is:

- We support the proposal to require integrated and non-integrated bodies to include carers in the planning, shaping and delivery of services. We believe it is important that carers and people who use services are involved in determining the types of support and services that should be available in their community. There should also be more creative methods of engaging carers in much more localised dialogue as carers can find it difficult to attend meetings and forums due to the demands of their caring role.
- We believe that young carers should have an opportunity to become involved in shaping services in their community. This can be done using methods which are age

appropriate, in partnership with young carer support projects, such as young carer dialogue and the Scottish Young Carers Festival.

- We support proposals to enhance legislation on the involvement of carers and young carers in care planning for the person they care for and in shaping the support they need to help them manage their caring role and have a life outside caring. We believe that the knowledge and experience of carers should be recognised and valued in care planning and that they (and the person they care for) are the experts in deciding what services and support is needed.

## **Planning and Delivery**

In relation to the government's proposals on planning and delivery our position is:

- Carers believe that there should be statutory provision for local authorities and health boards to involve and collaborate with carers and carers' organisations in the development of a local carer's strategy. These should be connected to the national carers' strategy.
- Carers believe that young carers' strategies should also be developed. 166 respondents felt that a Strategy for Carers should also include Young Carers within same plan, (this should also include young adult carers and define the support for carers affected by bereavement.).
- This should be a distinct part of the carers' strategy with the needs of young carers considered alongside adult carers in a local area. Not all young carers will be accessing children's service and therefore may not be covered by a Children's Services Plan.
- Carers believe that local authorities should ensure that there are sufficient services in their area to meet carers' needs. There should be a definitive list of universal, free services that are available to all carers and that form the core services provided by carers' centre's and services. This would be the minimum standard for services to provide for carers. In Angus SDS Implementation Group is developing a community information portal using the A.L.I.S.S search engine. This will also be cross referenced with the Third Sector Interface website where 902 voluntary sector groups and organisations are listed.

## Additional Proposals

In addition to the proposals outlined by the government, we believe that legislation could be strengthened by the addition of the following proposals:

### Carer Identification

63 carers agreed that the GP register should be linked to actions to support the carer, such as a Carers Support Plan and referral to a local carer support organisation. A further 54 said that local authorities should have a carers register. 153 said that both the GP practices and the local authority should hold carer registers. There should be a named person within each practice grouping to lead on carer support. This person should also be responsible for informing the carers centre that the cared for person has died to allow the local centre.

#### Best practice example

In Angus a preventative carer's assessment and support service targeted at carers and cared for people over the age of 60 years was developed through the Change Fund. We have improved co-production of support to carers by co-locating Carer Support Workers within local medical centres. We work in partnership with local medical centres, particularly practice nurses to ensure that their carers registers are up to date and that all carers had been offered a carers health check. From 1.12.12 to 19.08.13 the number of referrals from this source was 123, an increase of 111 from the same period the previous year. From these referrals we went on to complete 81 Carers Information and Support Plans. (Angus Carers Centre assessment process).

A sample of data from Monifieth Medical Centre shows that 39 carers attended for a carer's health check (of 44 appointments offered). 11 of these carers were not known to the Angus Carers Centre.

The appointment of carers' leads within individual practices may also be beneficial. Many carers' services maintain close links with local GP practices, which can be very useful for those carers who do not wish to have a carers' assessment or who are not eligible for one, as they are able to access significant amounts of support from the carers' service. However, these links with GP practices are often supported by funding streams such as Reshaping Care for Older People, so their continuation is not guaranteed. These projects and initiatives would benefit from Health Boards monitoring the practice's compliance with the GP contract.

### Carers Views

- ✿ *Joined up thinking at all levels*
- ✿ *This would ensure that no carer "slips through the system".*
- ✿ *Not all carers look upon themselves as carers, and don't always ask for help due to pride*
- ✿ *My local health centre is doing 'quite' well – identify me but don't ring up*
- ✿ *If not, how will they know numbers/need and respond appropriately*
- ✿ *Obviously – a 'policing authority' with 'clout' to ensure compliance is necessary*
- ✿ *Yes but will need auditing regularly*
- ✿ *Yes because GP practices vary in the care of patients and all GPs care enough*
- ✿ *Govt should ensure that health boards acknowledge the existence of carers and involve them in decision making*
- ✿ *They should have to be responsible for providing all necessary information on both the carer and cared for person(s)*

### **Portability of assessment for carers and cared for**

- Carers' views on this were fairly evenly split. 27 said the local authority where the carer resides should pay for the carers support and 36 said it should be the locally authority where the carer resides. 37 were unsure or did not reply. Some carers wanted the local authority in which they live to carry out their carer's assessment and provide any subsequent support; other carers believe that as the cared-for person's local authority is benefiting from the carer's presence and provision of care, it is this local authority who should support the carer.
- In some situations, the carer may eventually move from the local authority area they live in to the local authority of the cared for person. In these circumstances and where the 'original' local authority has carried out an assessment, we believe it would be beneficial for the carer's assessment outcomes to remain in place for a specified period whilst they are awaiting a new assessment from the new local authority. This will provide continuity of support to the carer to ensure they are not left unsupported. We would recommend that the period of time should not be less than six months.

### **Former Carers.**

- All too often former carers report that when their partner, who they have been caring for, dies then it is if they become invisible overnight. Their financial situation may be affected as their carers allowance and other benefits change and they have many changes to deal with at a time when their emotional strength is low. The Carer Support plan should include recognition of this difficult time for cared and to, at a minimum, have a signposting service to ensure the former carers are not forgotten about.

**Best practice example** Within Angus Carers Strategy 2013 - 2016 a commitment has been to "Support carers when their caring role comes to an end". Those who became 'former carers' through bereavement tell us that without the support of other former carers they received at Angus Carers "New Dawn " monthly lunches support they would have been left isolated, without anyone else to understand their situation.

### **Hospital Discharge**

- 180 carers agreed that there should be Duty on health to inform and involve carers in hospital discharge procedures. Where the care provided by an unpaid carer is included within a hospital discharge plan, they should be able to specify how much care they are willing and able to provide.

- **Feedback on carers' experience of their involvement in Hospital Discharge was very mixed.** It was felt that positive experiences came from the outlook and actions of individual staff where as negative experiences were more systemic and the need for more staff training on the role of the carer was required.

- ✿ Writer is experiencing coping with hospital discharge and finding the system in place is very supportive
- ✿ Often care plans are non-existent, leading in mental illness to be a reoccurrence
- ✿ Depends in the carer, age et
- ✿ Yes- otherwise people could be discharged with no service in place
- ✿ Otherwise it would be chaotic
- ✿ It would be more cost effective less likely to be re- admitted
- ✿ This is very important as plans in the community are not always made or implemented even though they should be
- ✿ Absolutely to ensure support services are in place immediately after discharge or preferably before
- ✿ This has never happened in the times when my husband has been discharged and I have often found it very hard to cope
- ✿ Discharge plans and carers plans would eliminate tragic discharge consequences
- ✿ Should always try to coordinated and pre-planned with all relevant supporters
- ✿ This would be a good extension to the care plan approach meetings in place for patients
- ✿ Staff need to communicate with carers – we are not the enemy
- ✿ It is imperative as the carer should ensure plans are implemented
- ✿ I thought this was in place now, but I saw none of it in either my or my wife's recent strokes
- ✿ Yes – my mother was sent home aged 50, so having had a heart attack, collapsed lung and pneumonia and scans due to allergy to the swine flu we received no care help for 3 weeks – a disgrace
- ✿ Maybe in certain circumstances ignorance of home circumstances even to the extent of no input requested from domiciliary
- ✿ This is very important as plans are not always made or implemented even though they should be
- ✿ Absolutely - to ensure support services are in place IMMEDIATELY after discharge or preferably before"
- ✿ It is vital that individual carers and their supporting care teams are kept fully apprised of patients' potential needs - post hospitalisation/discharge - it is a vital part of their future care package!!

- ✿ This would be a good extension to the Care Plan Approach meetings in place for patients
- ✿ On a number of occasions I was informed by phone that my husband was being discharged - on a few occasions long before he was fit enough
- ✿ Must ensure wellbeing of both carer and client is considered to ensure health of both parties
- ✿ Hospital just ignore carers, I know from experience"
- ✿ Arbroath Infirmary and Stracathro Hospital helped out when I was busy sorting things and especially when major house events took place (house move)
- ✿ Have experience of patient being sent home to an empty house with no support when daughter (sole carer) was on holiday abroad"
- ✿ Consideration in discharge planning should always involve carer
- ✿ This would outline any issues the carers have about the forthcoming discharge
- ✿ Support the carer in the early stages of bereavement where appropriate.
- ✿ Yes they should introduce a duty on health boards for carers in hospital discharge planning
- ✿ They do this at most hospitals
- ✿ Too often they just discharge and walk away from it leaving everything to the carer"
- ✿ Pre-discharge meeting should include carers (this will help improve communication).

### Emergency and Anticipatory Care Planning

- We propose that the Carers Support Plan should include a duty to incorporate anticipatory care planning.

**Best practice example:** Angus Carers is developing a series of "Carers Conversation" in partnership with Healthcare Professional from Angus CHP. Advance Care Planning is a process of discussion between an individual and their care provider about their preferences, wishes, beliefs and values about future care. Its purpose is to provide guidance to inform future care decisions in the event that the individual has lost capacity to make these decisions. It should be offered during routine clinical practice. The concept of Advance Care planning is gaining momentum throughout health and social care settings. Last October a short section was included in Angus Carers centre newsletter entitled, *"Thinking ahead: Conversations before crisis for carers"* At that time 19 individuals replied and 6 carers were invited to attend an introductory planning session on the 3rd March.