

The Carer's Assessment: Carer's Support Plan

We want to make some changes to how we decide what carers' support needs are.

Carers who give a lot of care can have a carer's assessment. Carers ask the local authority to decide how much support they need to keep giving care.

Some carers don't like the name "carer's assessment". We want to change the name to "Carer's Support Plan".

Question 1

Should we change the name from "carer's assessment" to "Carer's Support Plan"?

Yes

No

Comments

Carers' were unanimous in regard to this change.

Citing the following:

- Carer's Assessments have felt to the carers as if they are being assessed as 'fit to care' as if it is some sort of test. The assessment lacks flexibility which is necessary for those who care for someone with a mental illness or dementia.
- *'I've never been offered one and yet I am expected to care 24/7...I didn't know how hard caring was going to be and no one tells you what you are entitled to'.*
- Support Plan – a much better title, less stigmatising, redresses the power balance between 'assessor' and 'assessed'.
- *'Support plan sounds better, assessment makes it sound like we are being tested. Wording of assessment- implies that is the way it is and stays, whereas a support plan implies things could change, which often helps mental health as mental circumstances change regularly. Carer's need to have a say in review timescale.*
- "Support Plan" gives recognition to the status of Carers.

Some local authorities do an assessment to decide how much regular care each carer gives. Some do not. We want to change this so that all carers will be able to have a Carer's Support Plan. It won't matter how much regular care they give.

Question 2

Should we change the rules so that all carers can have a Carer's Support Plan?

Yes

No

Comments

Yes. Carer's were unanimous in regard to this change.

Citing the following:

- *'All Carer's should have access to support plans and there should also be access to regular or necessitated reviews. All carers should be recognised as having rights in their own capacity'.*
- Currently those caring for someone with a mental illness find it difficult to access Carer's Assessments due to the nature of their caring role, which differs from that of caring for someone with a physical illness and the eligibility criteria that is considered necessary for this assessment. The role of the carer may involve provision of support to the ill person in a number of ways – by phone, visiting hospital over a long period, ensuring that the cared for person is coping or they may in fact live with the ill person and provide support to assist the person to recovery and live with fluctuating mental health challenges.
- *For those who care for someone with dementia it is an increasing burden both physically and mentally. Change can occur quite dramatically in the cared for person and a support plan that is flexible is essential. Reviews of the support plan needs to be at times to suit the Carer's circumstances rather than at a time set by any authority.*
- Care and support comes in many forms. This proposal would need to recognise all those modes of care, and also the importance of that care to the carer.
- *Recognition that care may be given by many people in a family not just one Carer and that there may be an impact that needs to be considered fully in any support plan.*
- *'Being on your own with the person you care for is hard, you feel isolated and depressed, it's a long day to fill.*
- *"We can't always see what is going on for the cared person when it entails mental health"*
- Carers often have to care for more than one person – however again due to the criteria for assessment it may be only one aspect of their caring role that is assessed.
- *'When you care for more than one person, your needs are different. Life does not sit in little boxes, in this case you are only getting half of your role assessed. If the government go ahead and change the assessments they have to factor in a flexible approach to the questions within the paperwork allowing most of the needs of the various carer roles to be captured'.*
- One carer had had an assessment 4/5 years ago and has had no review. It should also have a clear system of when the assessment takes places and how often it is reviewed so the carer knows what to expect.

- A support plan should include the giving of information and advice as well as support and signposting to relevant agencies for a range of issues.

The person being cared for has to qualify for support from the local authority to get a carer's assessment. But some people don't need that kind of support or don't want it.

We want to change the rules so that the person being cared for doesn't have to qualify for local authority support.

Question 3

Should the person being cared for have to qualify for local authority support to get a carer's assessment?

No

Comments

- Regardless of whether or not the person affected by a qualifying condition is receiving LA care or not, the carer has a right to a support plan.

Carers can ask their local authority for an assessment (Carer's Support Plan). Not all carers know that they can ask for one. We want to change the rules so that local authorities offer a Carer's Support Plan to all carers.

Question 4

Should we change the rules so that carers can ask for a Carer's Support Plan or be offered one by the local authority?

Yes

No

Comments

- Making carers aware of their right to a Carer's Support Plan should be everyone's business and various routes for this must be catered for. Not all Carers will require support from the local authority and may find the support they need in the voluntary sector.
- Carers should be made aware of their right to a Support Plan as soon as possible and any scheme should be well promoted along with the various routes for this. They should then

be able to self-refer or assisted to do so. Not all Carers will want this but should be able to request one in the future or as needs change.

- Getting my request for support passed around with no real help. This can be very difficult to deal with. Some of the reasons for this are as follows:
 - i) Lack of knowledge
 - ii) Passing the buck
 - iii) Not linking us in to the right support services
 - iv) The support has to be there in the first place
 - v) Not flexible enough

The rules say that a carer's ability to give care is being assessed. Some carers don't like this. They think it is saying they are not good enough at giving care.

We want to change the rules so that the Carer's Support Plan doesn't say anything about a carer's "ability to give care".

Question 5

Should we change the rules so that the Carer's Support Plan doesn't say anything about a carer's ability to give care?

Yes

No

Comments

- The word "ability" has a lot of different connotations – it could sound as though a Carer has to go through some form of "test" which is demeaning. However some Carers may themselves suffer from ill health and the impact of caring in addition to coping with their own ill health may mean that they require further assistance in their caring role.
- *'Carers are not required to "give care", it is voluntarily done out of love. Carers may need support themselves on account of their own vulnerabilities and needs.*
- Suitability is another thing altogether! A Carer's suitability in terms of PVG status for example should be assessed.

It can take a long time for carers to get a carer's assessment. We think the people doing the assessment should tell carers how long they will have to wait. We think they should be told why if they have to wait longer.

Question 6

Should local authorities have to tell carers how long they'll have to wait to get a Carer's Support Plan? Should the local authority have to give reasons if carers have to wait longer?

Yes

No

Comments

- Yes. Carer's were unanimous that they should be informed about the length of time this would take if the local authority is charged with undertaking this.
- However it is hoped that there will be several routes that can be taken regarding access to 'support plans' and timescales should be put in place between the individual Carer and the agency undertaking support planning. Some Carers may need access to support in an emergency and common sense about how to address an urgent referral needs to be considered – not set against a timescale.
- Any slip in timescales by **any** agency should be communicated to the Carer and the reason for this.
- There should be a timescale set for when the offer of a Carer's Support Plan is made by the local authority, not just for when the Plan will be completed.

Not all parts of the country have the same services. Service users might not be able to get the same support if they move to a new area. They might have to wait until a new carer's assessment is done.

We think it should be easier for service users and carers to move to a new area. We think the Government and local authorities should work together to make this happen.

Question 7

How important do you think it is that service users and carers should get the same support if they move to a new area?

Comments

- Carer's feel that they should be able to access similar support in all areas of Scotland but that would require for all areas to work to the same criteria and to commission the same services which may not currently be available.
- *'Portability of Support Plans would be the ideal'.*
- Concern is also expressed regarding cross border issues.
- *More information on the practicalities of these issues would be necessary.*

Question 8

Should the Government and local authorities work together to make this happen?

Yes

No ●

Comments

- Ideally the Government and local authorities would work to make this happen. However we again highlight that due to our proximity to England and consideration of cross border issues we would need to have more information on how this would work in practice.

Information and Advice

It is very important that carers and young carers should have access to the best information and advice. This will let them make the best decisions about their support needs.

Carers tell us that things would be better for them if they got the right information at the right time.

Carers need to be given information and advice that they can understand.

Question 9

Should we make it a rule that local authorities have to have information and advice services for carers and young carers?

Yes

No

Comments

- The local authority should have a duty to "*ensure appropriate information and advice services are available*" as these types of services might be more appropriately provided through contracting with a range of **specialist** Third Sector organisations.
- '*Any service needs to help Carers awareness of what may come as part of their caring role rather than purely to react to a crisis – which of course is important but crisis may be prevented by having the right information and support at the right time*'.
- It is also thought it would be useful to set out the minimum requirements for such services and that information needs to be accessible to all.
- Carers of those with mental illness/dementia and learning disabilities are also strongly in favour of specific and specialist Carer Advocacy – particularly around the issues of legislation that may affect the person they care for – e.g. Mental Health (Care and Treatment) (Scotland) Act 2003 and Adults with Incapacity (Scotland) Act 2000.

- Carers also feel they would benefit from more knowledge around legislation and also around welfare and financial guardianship, power of attorney, rights and benefits etc.
- *"I think it is dangerous if we don't get the specialised advice and support- we need the strain taken off the carer"*
- You are undermined financially- looked down upon by the government and seen to be scrounging off benefits. "I am doing a full time job'.

The rules say that local authorities have to show their plans for carers' information to the Government. This won't be needed in future because the rules will tell all local authorities what kind of information they should give to carers.

Question 10

Do you think local authorities should have to show plans to the Government?

Yes

No

Comments

- Ensure this legislation conforms to Human Rights legislation. Include Carers support plans in Inspection of Integrated Care. As part of the inspection ensure that a random selection of carer support plans are inspected. Consult with carers as part of inspection.
- *Who do carers complain/appeal to?*
- Does the Ombudsman apply?
- *What is the overseeing body?*
- Plans should be regularly updated and reviewed
- *Specific person should be available in unit and liaise to give specific information and advice, like a booklet perhaps? Link worker?*
- Additionally, some carers expressed the following concerns;
 - Support doesn't cover support or transport, discrimination and disadvantage, no money in fund for external family travelling, childcare. No provision financially, childcare from Local Authority- doesn't cater for needs. Local Authority need to give support- put in legislation. Financial strain, lose benefit in hospital, travel etc. all a financial burden.

Support for carers

The law doesn't say local authorities have to support carers at the moment.

After April 2014, there will be a new law called the Social Care (Self-directed Support) (Scotland) Act. This will mean that local authorities will have to do a carer's assessment for every carer who asks for one or who is found to be a carer. It will be up to the local authority to decide if support is needed and if it will give that support.

Question 11

Should we make a rule saying that local authorities have to give support to carers and young carers who qualify?

Yes

If you said yes, please go to **page 8**

No

If you said no, please go to **question 12**

Comments

- Carer's believe that all those who are caring for someone should qualify for some aspects of support and that a distinction needs to be made between financial support and other forms of support, advice and information and signposting.
- *Greater clarity is required.*

Question 12

Should we keep the rules as they are now, and let local authorities decide if they will give support?

Yes

No

Comments

Carer's were unanimously against this.

One of the best ways to help carers and young carers is to give them short breaks. Short breaks let carers have time out from caring so they can recharge their batteries.

Short breaks can be holidays, leisure activities or meeting up with friends. They can include the person being cared for or just the carer.

We could make it a rule that local authorities have to give short breaks to carers.

Question 13

Should we make a rule that local authorities have to give short breaks to carers?

Yes

No

Comments

- Carers had varied responses to this. While some felt that there should be a rule about the provision of short breaks for Carers, they were aware that this would require an eligibility criteria to be put in place and that some Carers may not fit the eligibility criteria put in place. There would clearly be a financial implication for the local authority and the Carers of those with mental illness were concerned that they would not be able to utilise a scheme that had tight criteria. They also highlighted that it may be necessary for the local authority to give priority to those caring for someone with a physical illness or disability and they would miss out.
- *Mental health Carers who took part in the consultation highlighted the 'Short Breaks' fund that they can access through organisations such as 'Support in Mind Scotland' and felt that there was a better understanding of their need for a break from this provider and others in the voluntary sector. The criteria for this includes looking at the Carer's situation and that a support worker assists them to fill out the application. However they were aware that some Carers would not be aware of this and felt that there should be more promotion around the scheme.*
- 'The benefits of short breaks (however short) either just for the carer, the caree or together (eg Dementia Choir etc) are undisputed. The question is clumsily phrased however, and could include the duty to signpost to independent providers'.
- *'Short breaks are better through organisations like SIM- straightforward and easy'.*

Stages and Transitions

Things can change the kind of care a person needs. We call these **stages**. The kind of care a person needs can change. The carer might have to spend more time caring for the person. The carer might have to learn how to give new medicines or use new equipment.

Question 14

Should we change the rules so that the Carer's Support Plan helps deal with different stages of care?

Yes

No

Comments

- Carer's were unanimously in favour of this. However they were concerned about how the stages and transitions are defined and felt that they were not flexible enough and that they should be responsive to individual needs rather than purely the move of the cared for between age groups and services.
- *Recognition that there may be more than one person in the family who takes on the role of carer is required – for instance the impact of mental illness on siblings or the extended family.*
- An area that has not been considered in the consultation is that of 'the end of the caring

role' – by that we mean the death of the cared for rather than movement into long term care – although the transition into long term care has specific support needs for the Carer.

- *'Carers feel lost, lose identity, purpose, no job, social support, feel rejected in society'.*
- This can be a very difficult time and recognition from services of this would be extremely helpful and validate the role of the carer.
- Carers getting new skills/ training after the caring role.
- *'If you lose your job you can go into the job centre and apply for a similar job or get retrained to do something else. Caring may have been the job of the Carer for years and yearswhat do we do when that role stops?'*

We call it a **transition** when carers or the people being cared for grow up from children to adults. The change in their needs has to be looked at carefully so they keep getting the best support.

Question 15.

Should the new rules let young carers have a Carer's Support Plan if they are going to become adult carers?

Yes

No

Comments

Carer Involvement

We think that carers should be involved in planning support for the people they care for and for themselves. This means they get better support which meets all their needs.

Carers' organisations should be involved too when needed.

Question 16

Should carers be involved in planning support for the people they care for and support for themselves?

Yes

No

Comments

- Many of the Carers within mental health, learning disability and dementia are caring for people who may not be able to give consent for a variety of reasons – for instance they may lack capacity to give consent or due to the nature of the stages of mental illness may express that they do not wish for the Carer to be involved at their point of ill health.
- A common sense approach needs to be taken in these circumstances to establish whether care and support is currently being given or has been the wish of the person who is cared for in the past. There are some documents that could be used to establish this – the Advance Statement or Named Person documentation used under the Mental Health (Care and Treatment)(Scotland) Act 2003 or where there is clearly the intention that the Carer will provide support in the future.
- While it ideally would be with the consent of the cared for person due to the above this may be difficult to achieve and as long as there is no conflict with any related legislation and the role of the Carer in Adults with Incapacity Act, M H Act, Guardianship, Adult Support and Protect and Human Rights or other legislative documentation then the Carers wish to be involved where they have been providing care must be taken into account.
- Other aspects that have been highlighted that may help this process is the use of Advocacy services and other independent supports to support the involvement of Carers allowing them to be involved.
- An issue of involving the Carer in planning support if they care for someone who may be out of the Health Board area for a variety of reasons also needs to be taken into consideration.
- Again cross border issues have been identified and clarification is needed.
- *'Yes, we should be given the right and the say. We have the experience which could help the services get it right for us and future carers'*

Question 17

Should carers' organisations be involved in planning support for carers and the people they care for?

Yes

No

Comment

- Yes. Carer's organisations (and providers organisations) should work with their Carers to ensure that they have a representative voice and to bring that to the planning of services both for the Carer and for the cared for.
- More involvement at grass roots is required to ensure that this happens in an equitable way and that there is support for Carers to be involved at whatever level they are able to contribute due to the pressures of their caring role.
- Organisations that have independence and experience of involving Carers and the cared for should be consulted further to ensure that any system for involvement is robust.
- Provided that where the cared for person has capacity, or attorney/guardians are consulted in line with related legislation.

Carers are equal partners in care. They have experience and know things about the person they care for. Health professionals should listen to carers when planning care.

We want to change the rules so that carers have to be involved in planning care. If the person being cared for wants this.

Question 18

Should we change the rules so that carers are involved in planning care?

Yes

No

Comments

- Carers wish to be consulted and given appropriate information and independent support if they require it to be involved. Again this highlights the need for Carer's Advocacy.
- NHS should be obliged to recognise the authority of Guardians and of attorneys or a Named Person.

- However there is also a concern that there would be a pressure on Carers to provide care or input into care planning even if they do not wish to be involved and this must be taken into account.
- The question does not take enough account of the various legislative processes and some of the principles of the law with regard to respect for Carers as cited in the Millan principles of the Mental Health(Care and Treatment) (Scotland) Act 2003 and other relevant legislation. These areas need to be highlighted to all statutory bodies.
- Siblings and the wider family are also often involved in providing care and this needs to be taken into account.

Young carers also want to be involved in planning support for the people they care for and for themselves. They say that health professionals don't always listen to them when making decisions.

We want to change the rules so that young carers are involved in planning care. If the person being cared for wants this.

We also want to know what you think about young carers being involved in planning support for the people they care for and their own support.

Question 19

Should we change the rules so that young carers are involved in planning care?

Yes

No

Comments

- Young carers should have the same rights as adults and given the support they require to ensure that their views are taken into account.

Question 20

What do you think about young carers being involved in planning support for the people they care for and for themselves?

Comments

- As above.

Planning and giving services

Most local authorities have plans for carers. Some are made with help from local Health Boards. Some local authorities have plans for young carers.

We think that local authorities, Health Boards, other organisations and carers should work together to make plans for carers' support.

Question 21

Should we make a rule that all these organisations must work together with carers to make plans?

Yes

No

Comments

Should these plans be looked at and updated every three years?

Yes

No

Comments

- Carers need to have flexibility in any plan that is put in place and should be the ones that highlight at a personal level if they need updated and not be left to statutory and not statutory organisations alone to determine the time to update them. There may be developments at any level that needs to be taken account of and this is not based on a specific timeframe either on an individual or strategic level.

The law doesn't say that local authorities with Health Boards have to give carers counselling, advocacy, short breaks and other kinds of support. We think this should change.

Question 22

Should we make it a rule to have a range of services available for carers and young carers?

Yes

No

Comments

- Building on existing services to cover all the areas that Carers require is essential and the majority of these services will be within the voluntary sector. More account of the various needs of the Carer needs to be considered.

- Again access to specific Advocacy for Carers particularly around legislative processes (although not exclusively) is highlighted as a need.
- Capacity should be established to support carers after their role has come to an end, with exit strategies built into Carer's Support plans.
- Local Authorities and Health Boards should encourage the development of the social capital and expertise that carers develop collectively as well as individually.

Telling who is a carer

We need to be able to tell who is a carer so they can get a carer's assessment (Carer's Support Plan) and support.

This is not always easy. Some people don't think they are carers or don't want to be called carers.

Doctors (GPs) are usually the first people to find out if a person is a carer. Doctors keep a list of carers and they use this to refer carers for support. We don't think doctors should keep a list of carers. We think Health Boards should share ideas on how to raise awareness about carers in doctor's surgeries.

Question 23

Should it be a rule that doctors (GPs) have to find out who is a carer and put them on a list of Carers?

Yes

No

Comments

- *'Being "carer aware" is everybody's business'.*
- Currently registers of carers might be held by a variety of organisations, including GPs but it is not clear how these are established or maintained or what the purpose of these registers is. Carers felt that they need to know what would be done with this information and essential that they are given the opportunity to agree or disagree with their name being held on any register and the clear purpose for it.
- While some Carers strongly agreed that GP's should have a register in order that they could check up with the Carer about their own health and situation, some carers felt that they were just not recognised as having a caring role so that a whole culture change would be part of this process.

- *'I do think GPs should keep track of carers and check in with them to see how they're doing'.*
- *'The GP- can put you off from identifying yourself as a carer as they seem to think we are only carers when the person cared for lives with us'.*
- There was also a question from some Carers as to how this would be funded and whether it would be of any real use to the Carer.

Question 24

Should we make a rule that Health Boards share ideas on how to raise awareness about carers in doctor's surgeries?

Yes

No

Comments

- Carers felt that this should not be the sole responsibility of GP's but should equally be the responsibility of Social Work and the wider NHS although they may attend their GP in a crisis and they should have an awareness of the supports available for Carers and the impact of caring on their own health and wellbeing.
- Carer's felt that they needed to know more about how this would work in practise.
- See previous comments at 23.

Question 25

Should the Government ask Health Boards to make sure that doctors (GPs) are keeping their list of Carers up to date?

Yes

No

Comments

- Under integration the local authority will be the governing body and therefore they should have the responsibility to monitor this arrangement

When the carer and the person being cared for live in different areas

Some carers live in different areas from the people they care for. Each area might have a different local authority. The carer might ask their local authority for a carer's assessment. But their local authority doesn't have to support people who live in other areas.

We think it would be better if the assessment was done by the local authority where the person being cared for lives. But different local authorities have different ideas about this.

We need to decide which local authority should do the Carer's Support Plan and which one should pay for the support. It might be best if both local authorities worked together to plan and pay for the support.

Question 26

Which local authority do you think should do the Carer's Support Plan?

Comments

- Carers felt the lead authority for the Carer Support Plan should be the one where the carer resides rather than the one where the cared-for person resides. The point of Carer Support Plans should also be to provide early intervention and prevention and to help signpost carers to relevant organisations that might be able to provide support and the wide range of services they may require.
- Some cared for people are also sent out of region for care, treatment and this may be lengthy and this needs to be taken into account.
- *'This should be the responsibility of the integrated authority surely? Have the writers of this consultation not heard of the Public Bodies Bill or the Christie Report?'*
- By making the authority in which the carer lives responsible it identifies the carer's rights as relating to the carer's own needs, rather than as an "add on".

Question 27

Which local authority should pay for the carer's support ?

Comments

- Carers support should be paid for where the carer lives and the same should go for the cared for.

Question 28

Should the Government and local authorities come up with guidelines for this?

Yes

No

Comments

- Guidance also needs to include the promotion of rights.

Where to send your answers

Please send your answers to:

CarersandYoungCarersPolicy@scotland.gsi.gov.uk

Or to:

Carers Branch (Consultation)

Adult Care and Support Division

Directorate for Chief Nursing Officer, Patients, Public and Health

Professions Director-General Health and Social Care

The Government

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