



National Carer Organisations: response to consultation on proposals for carers' legislation

The National Carer Organisations are Carers Scotland, Coalition of Carers in Scotland, Crossroads Caring Scotland, MECOPP, Carers Trust Scotland, the Scottish Young Carers Services Alliance and Shared Care Scotland.

We believe we can deliver more for carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to carers. It is our shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care.

The National Carer Organisations consulted widely with carers and carers' organisations in order to inform this consultation response. Quotes and statistics from the consultation events that we held are used throughout this document, and the full set of data that was collected has been submitted as an appendix to this consultation response. We consulted with over 500 carers as part of this consultation exercise, through a mixture of online questionnaires, social networking, small group discussions, large consultation events and carers' forums.

1. The Carer's Assessment/Carer's Support Plan

There are a number of proposals to change Carers' Assessments to increase take up and encourage carers to come forward for support. In recent research¹ more than a third of carers were receiving no practical support, with more than 80% saying that caring had made their health worse; 40% have given up work to care.

In earlier surveys with carers in the development of the Carers Rights Charter², we found that despite a legislative duty to offer carers assessments, only 38% had been offered an assessment with 18% offered a self-assessment. However, of those offered an assessment only a third had *actually received one*.

More than half of carers said that their carer's assessment was useful (27%) or partly useful (38%). However, the majority (69%) reported that their assessment led to no new support for their caring role.

We therefore believe this is vital to extend access to Carer's Support Plans to ensure that carers have the right support, at the right time, to help them care and have a life outside caring.

¹ State of Caring 2013, Carers UK/Carers Scotland

² Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

In the first instance, we support the name change from Carer's Assessment to Carer's Support Plan. We believe that this more accurately reflects their purpose, which should be to plan what support can be provided to help carers manage their caring role. Many carers do not like the term Carers Assessment and this is reflected in the response to our survey of carers where a large majority (86%) agreed that this was the right approach.

We support the removal of the regular and substantial test and the proposal to place a duty on local authorities to offer all carers the Carer Support Plan. This is supported by carers with whom we consulted, with 99% being in favour of this approach.

"If it is not a duty, it won't happen."

"It is important to remove the 'regular and substantial' test and extend Carers Support Plans to all carers. This will mean early identification and should help more carers receive appropriate support. The support plan should be based on carers needs and be regularly updated to ensure that, as young people and carers grow older, plans continue to meet needs. It is essential that carers are given support to have lives outside caring."

We believe that this will enable carers to access the information and support they need earlier, preventing greater cost at a later stage. However, it is vital to ensure that in responding to increased take up, local authority and local carer and community supports are sufficiently resourced.

"Monies given to local authorities should be ring-fenced for the Carers Support Plan."

"Prevention must remain at the heart of Carer Support Plans and eligibility criteria must reflect that so councils do not default to crisis only intervention or set the eligibility criteria so high that only carers in desperate situations get a Support Plan completed."

We agree that statutory guidance should underpin the depth of Carer's Support Plans but that the scope should be informed, in all cases, by the needs and wishes of the carer. The majority of carers (85%) with whom we consulted also agreed that statutory guidance was required and with the proposal to have different levels/depths of Carer Support Plans (89%).

"All carers should have the same opportunity to identify areas where support may be needed. If a lower level is used the carers may not be aware of all the support which may be suitable/available."

"Each carer's role is different, with different needs and help required. The support plan should meet the needs of the carer and the cared-for person and should be unique to their needs."

"Yes because things vary and it also depends on the context of the carer's other commitments."

Furthermore, we agree that statutory guidance should be in place to describe what should be included in discussions for the Carer's Support Plan, not least a carer's right to choose the level

of care (if any) they are willing to provide and their right to a life outside caring. When we surveyed carers³ less than a third knew that they could decide what level of care they were willing and able to provide and only 8% had been told that they were able to make choices about their caring role. In our parallel survey with providers, 70% of professionals knew that carers had this right but only 16% said that in their experience carers were informed.

In supporting proposals for statutory guidance, we have some concerns at the proposal not to legislate for a minimum set of issues to be discussed. We believe that this may result in inconsistency. In our consultations with carers, 96% said that the Scottish Government should legislate to provide a minimum standard for issues to be discussed.

Moreover, whilst 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 Carer's Support Plan, we are unsure that this will solve the current situation where carers can wait many months (indeed years) for their Carer's 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 (e.g. not exceeding 12 weeks) to ensure that carers do not reach crisis point before they receive support. This timescale should reflect both the time for local authorities to undertake an assessment and also to provide services that carers are eligible for.

"They should also agree a timeframe and not have people waiting weeks."

"Been trying to get help for 15 months. There should be a published process which is consistent. This should also have a timeframe in which this must be done."

The process for reviewing Carer's Support Plans should be clearly outlined in statutory 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.

We welcome the duty that will be placed on local authorities to inform carers about the Carer's Support Plans. However, this duty should be extended to acute NHS services and to new integrated primary health and social care services.

"Identification of a carer is crucial for their entry into the systems that will support them. As we have no idea how much care carers will provide from day one, due to the nature of medical condition(s) of the cared-for person, it should be the duty of both the NHS and local authorities to be aware of carers and provide information from the first point of contact."

We support the remaining proposals to remove those legislative provisions that place barriers to carers accessing support including the assessment of "ability to care" and the need for the cared-for person to be receiving community care or children's services. In our consultations with

³ Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

carers, the majority agreed that the provisions to remove the need for the person they care for being in receipt of services (51%) and reference to a carer's ability to care (96%) were welcome.

"If the cared-for refuses help or cannot access help, then the carer's needs still to have an assessment in their own right."

"It would be wrong to exclude any carer because the person they care for perhaps doesn't want community care or other support. These are perhaps the carers who need support most of all."

"Yes it shouldn't matter that those you care for don't receive any other services. That might be down to choice, the carer may not have been given a choice or local cutbacks will lead to the person being cared for not receiving services. The carer may still have a caring role and may need support."

"Previous Carers 'Assessments' in West Lothian felt more like an examination of the carer's competence and ability to care. I never felt it was supportive."

"I would however like to be reassured that if I'm old and frail, I won't be left to move and handle my some. We should be aware of the carer's capability to undertake caring tasks rather than judge their ability for tasks. However, training should be provided where tasks require training for professionals."

In responding to our consultation, many carers highlighted the importance of ensuring that not only was a Carer Support Plan provided but that the support and outcomes identified must be met. This is discussed further within this response under proposals around a duty to support carers.

"...Getting to local authorities to actually DO anything with this assessment is the problem. All too often the assessment is marked; 'no service available'."

"...this duty to offer [a carer's support plan] must be coupled with a duty to deliver the services required to meet needs identified. Where those needs cannot be met – given current resource restrictions – this 'unmet need' must be identified as such so that the duties and provision of the Support Plans meaningfully contribute to the long term planning and commissioning, otherwise pretty pointless!"

We also support the option to devolve the process for undertaking Carer's Support Plans to the third sector. However, our position is that there needs to be an understanding that the duty remains with the local authority and there must be a clear process for responding to the needs identified through the assessment. In practice, this should include identified workers within the local authority linking with the relevant third sector organisations. Devolved Carer's Support Plans must also have the same standing as those undertaken by statutory bodies.

"Carers Centres are best placed to carry out carer support plans as what they do is all based around carers' needs."

2. Carer and cared-for person living in different local authority areas

When a carer lives in a different local authority area than the person they provide care for, a number of issues may arise which require clarification. Caring at a distance also raises the question about which local authority should provide support to the carer. This is not a significant issue at the moment as most local authorities do not provide direct support to carers, but may become more of an issue in the future, subject to legislative change, i.e. the proposed duties on local authority to carry out carer support plans and provide support to carers. Local authorities must also consider who meets the cost of undertaking the Carers Support Plan and in funding and providing support.

It is likely that 'caring at a distance' will increase due to changing family structures and migration patterns. In addition to providing care, families may have to contend with long journeys and the additional emotional strain on not being 'on hand' should an emergency arise.

The Scottish Government have not taken a decision on this, acknowledging this is new territory for them. However, it recognises that it might be more practical for the local authority in which the carer lives to undertake the Carer's Support Plan and to collaborate with the local authority in which the cared for person lives. It is also suggested that the local authority in which the cared for person lives might reimburse the local authority in which the carer lives for any support provided to the carer.

We agree that the local authority in which the carer lives should undertake the Carer's Support Plan and seek to recoup costs from the local authority in which the cared for person lives. In some situations, the carer may move from the local authority they live in to the local authority of the cared for person. In these circumstances and where the carer's original local authority has carried out an assessment, we believe it would be beneficial for the Carer's Support Plan to remain in place unless the carer's circumstances or needs change. This will provide continuity of support to the carer to ensure they are not left unsupported.

Emergency and Anticipatory Planning

The need to ensure carers are able to discuss and plan for emergencies has been recognised by the Scottish Government, CoSLA and partners in the Strategy for Carers in Scotland in 2010⁴ as an important element of supporting carers. We believe that the proposals on Carers Support Plan must include a duty to incorporate emergency **and** anticipatory care planning.

Enable Scotland in their report "Picking up the Pieces"⁵ recognised that many carers do not have a written plan for an emergency or should something unexpected happen. The report found that whilst some carers may have informal arrangements, such as support from friends and families, there were key groups of carers who were particularly at risk and for whom an emergency situation may indicate a future crisis situation, for example, deterioration in the

⁴ 10.10 This is linked to **emergency planning** - a rapid response service - when there is a need for such a service. Carers should be supported in proactive planning for emergencies and unexpected events.

⁵ Picking up the pieces: Supporting Carers with Emergency Planning, ENABLE Scotland, September 2012

carer's health or an increased in the needs of the cared-for person. Moreover, the research found that only 2 out of 16 respondents said that a policy on emergency planning existed in their area, although the majority stated that emergency planning should have a high priority

The National Minimum Information Standards also clearly identify that a Carer's Assessment (in the future Carers Support Plans) should include information *"determining whether the caring role is sustainable and should identify current and potential risks to the carer's health and wellbeing as a result of the caring role."* The Standards include key questions on supporting the caring role and planning for the future. These are:

Supporting the caring role

1. Are there any measures in place for emergency or crisis planning?
2. If yes, what are these measures?
3. If not, what would need to be done if an emergency arose?

The future (explore concerns and plans for the future)

1. Are there any potential changes in the future, which may affect your caring role?
2. If yes, what are these?
3. What can be done to address this?
4. What are your hopes and plans for the future?

We propose that the Carers Support Plan should include a duty to incorporate emergency and anticipatory care planning. These minimum standards and the recommendations for emergency and anticipatory provided within *"Picking up the Pieces"*, informed by carers, offer a way forward to achieve this.

3. Information and Advice

We agree that local authorities should ensure that information and advice about the Carer's Support Plan (and for support to carers and young carers) is provided, and therefore support the proposal to place a duty on local authorities to establish and maintain an information service. However we have concerns that local authorities may try to establish their own services in order to reduce costs rather than resourcing and supporting existing carers' services. Carers' centres and services have a very important role in supporting carers, and whilst this proposed duty includes a requirement that information should be provided about support to carers provided by third sector organisations, we believe that this does not go far enough towards recognising this important role. As most areas in Scotland have a carers' centre or carers' service, these services should be supported to continue their work as they have already established a local presence.

Carers who responded to the online questionnaire and participated in consultation events are completely in favour of the proposal to place a duty on local authorities regarding information and advice provided to carers, provided that carers' centres and services were not overlooked.

"They should have a duty to inform re services available such as respite, community care, benefits. They should have a duty to ensure that a good quality service exists."

“Use the existing services as a starting point.”

Many carers were not in favour of a local authority operating its own in-house carer support service; sometimes this was due to bad experiences with social work or other local authority services, but mostly it was because they had experience of third sector carers’ centres and services, and valued them hugely.

“Carers’ centres are invaluable in advocating.”

“Carers’ centres are so important. Social workers cannot replicate this.”

“[The service] should be provided by a local independent carers’ centre who can provide independent advocacy and advice, not by social workers.”

If there is to be a duty placed on local authorities to establish or maintain information and advice services for carers, there will need to be a universal standard for carer information and advice services, which would be the minimum standard for any new services to provide. Carers must also play a central role in deciding who provides the information service in their area, taking account of existing services and recognising the strengths and benefits of existing services. This may be covered by the proposals around carer involvement in service planning and delivery, but the importance of involving carers in service design, planning and delivery must not be overlooked.

Local authorities will have to consider whether resourcing currently existing carer support services will be more appropriate than establishing a new service. The range of information and advice available from a service would have to be broad enough to cover a whole range of caring situations and all aspects of carer support. Independent carers’ centres and carers’ services can already provide expert information and advice at this level. In most situations, it will be better to support an existing service that has a well-known presence in an area, that carers already know and trust and that is skilled at identifying hidden carers and those who are new to caring.

“It’s been proven in the past that if it’s only one organisation’s responsibility to provide info, that it can go wrong. We need as many people keeping us up to date as possible.”

“The carers’ centres are well set up to do this work and their expertise should be recognised and paid for.”

“The carer needs this information to see what’s available and what their rights are etc. because the carer simply doesn’t have the time or means to gather this information.”

4. Carer Information Strategies

Support for carers from Health Boards must be maintained; if Carer Information Strategies are abolished, there must be a continued focus from the health sector in identifying, informing and supporting carers, including directing resources to carer support as a continuation of current CIS funding. Many Health Boards provide carers’ centres and other carers’ organisations with funding through Carer Information Strategies to provide information to carers.

Carer Information Strategies are a good way of ring-fencing money to support carers and there is a risk that Health Boards may not protect money for carer information and advice without them. . Carer Information Strategies have also been effective in raising awareness of carer's issues within health services and we are concerned that without such a focus, the progress made will be lost. Carers and carers' organisations must be involved in local planning if Carer Information Strategies are abolished – this is covered at a strategic level by integration strategic planning groups, but may not include carers and carers' organisations in enough depth

Some carers were not really aware of the existence of Carer Information Strategies and were not sure how the proposed repeal would affect them, but many carers who took part in our consultation are broadly not in favour of repealing Carer Information Strategies.

“Health boards are still slow to understand the needs and role of carers and involve them fully. The duty to provide information keeps them focused on the existence of carers.”

“CIS required [to continue] at least until there is more evidence of how the integration of H & SC is working on the ground”

“Carer information strategies help ensure that money is used for carers. It is essential that carers and carer organisations are included at strategic level.”

“CIS: must get feedback from services so they know how much £ is needed, then ring fence it.”

The mechanisms for directing resources to carer support would need to be nationally agreed and embedded within the new integrated partnerships to ensure that health boards and local authorities are able to respond to the requirements of their local communities. Carers and carer support services are not currently as involved in health and social care integration as they would need to be to ensure that funding and support is maintained. Additionally, it is not particularly clear from the consultation paper how integration of health and social care will replace the support that is provided and funded through Carer Information Strategies, even if the mechanisms for directing resources to carer support are embedded within the new integrated partnerships – we would need to hear more information on exactly how the Government would ensure that the funding they provide is protected.

“Recognise 3rd sector as equal partners in integration and give them the status they deserve in partnerships at a strategic level.”

“Need to continue and learn from good practice and share. This is an evolutionary thing that can be more integrated in the future.”

In addition, whilst supporting the capacity of existing carers' services to provide information and advice to carers, local authorities, health boards and integrated bodies must also ensure that information and signposting to this and other support is also easily accessible to carers in a range of community settings.

“It is the local authority’s duty of care to the care to make sure that all relevant information is easy for the carer to obtain whether it be online or leaflets in GP surgeries, libraries, post office, hospitals etc. Maintaining and updating information is also important.”

“Not only should they establish and maintain an information and advice service but local authorities should be ensuring that carers know about it, promoting it far and wide, through voluntary sector organisations and community settings where carers and people go e.g. libraries, health centres, post offices, banks, shops, council offices, police stations, bus stops, local village shops etc.”

5. Support to carers

“We don’t really want that much – some acknowledgment and a little support” (carer, Alloa)

The majority of carers who either attended a consultation event or responded to our online survey indicated that they agreed with the proposal to introduce a duty to support carers and young carers linked to an eligibility framework.

94% of carers who responded to our survey gave a positive response to this proposal and at many of our consultation events the approval rate was 100% (Stirling, South West Glasgow, Alloa, North Lanarkshire and Borders) The lowest response came from those who attended the Coalition of Carers meeting in Glasgow where 63% of participants indicated that they were in support of this proposal.

“Carers are frustrated that they have a right to a carer’s assessment but no right to the support and resources they are assessed as needing”

Carers were clear that they wanted a right to support and greater transparency in regards to what level of support they are eligible for. They understood that by introducing an eligibility framework this could result in some people losing out, either because they do not meet eligibility criteria, or because the level of service they currently receive could be reduced. However, they felt that this was a fairer way of allocating resources and would help to address the postcode lottery and bring some clarification to the question ‘What am I entitled to?’

*“I have real reservations about how this will be interpreted but the need for a **duty** to provide services either directly or indirectly is clear.”*

In terms of carers who would not meet eligibility criteria there was universal support for the proposal to retain the discretionary power to support carers in these circumstances. This would include forms of preventative support, such as support from a local carer organisations or condition specific organisation, short break voucher or grant schemes or signposting to local community support.

“There should be a duty to support carers against an eligibility framework, but local authorities should still have a power to support carers who don’t meet all the necessary criteria.”

Why carers support the proposal

Knowing your entitlement

This was the most commonly voiced reason for carers supporting the duty. Many carers talked about the difficulties they had experienced with working their way through the system and accessing appropriate support. Phrases such as ‘battling’ ‘fighting’ ‘hitting the wall’ were used to describe how frustrating the process was.

“It should be a duty to provide a break for carers, and carers should not feel like they are begging”

Carers felt that if local authorities have a duty to provide them with support and publish their eligibility criteria they would find it easier to navigate the system and access support

Greater consistency

At the moment there is little consistency in what support is available to carers from one local authority to another. Indeed there are often inconsistencies in the support carers can access within local authority areas, either because it is dependent on the care manager, the tenacity of the carer in accessing support, or the suitability of available services for the cared-for person. Carers UK State of Caring Survey (2013) found that nearly a third of those caring for over 35 hours a week receive no practical support with caring. At our consultation events there was a great variation in the level of support carers were able to access, with some carers still struggling to access support despite having an intensive caring role

*“Protects **all** carers not just carers who are lucky enough to live in a well-resourced area”*

“We need common sense legislation that ensures equality and maintains standards of support”

“There needs to be equality across the board – everyone assessed using the same eligibility criteria with the same entitlements to support and resources”

Recognition

Carers felt that the government’s decision to bring forward legislation for carers was an important step in recognising carers and their contribution to society. It also recognises the need to support carers and places a statutory responsibility on local authorities to support them for the first time.

“I feel it is important that a Duty is placed on the local authorities to recognise the role I play and should provide me with appropriate supports which meet my needs”

“About time - heavy end carers should be prioritised as a matter of urgency”

“There is a need for Carers Legislation to ensure carers are seen as a priority in Scotland”

Investment in services/Better use of resources

If local authorities are required to provide support to carers who meet eligibility criteria there will be a greater onus on them to ensure they have sufficient and appropriate provision in place to meet demand. Many carers we spoke to believed that money could be spent more wisely within the current system and those savings could be re-invested. However they also believed additional resources would be required and that local authorities should invest in carer support with a view to sustaining the caring population. This investment must be weighed against the known benefits of preventative support and the savings made by crisis prevention and avoiding the need for more costly interventions. Overall they felt that the Duty would require local authorities to prioritise carer support and start to ‘fill in the gaps’ that currently exist in provision.

“Impact will be that more resources will be required or existing resource will be diluted (a see-saw effect) However, if done in partnership between local authority and health with pooled budgets it will achieve better outcomes for people.”

“There are different degrees of caring so there needs to be eligibility criteria to ensure a fair allocation of resources”

“The ‘marketplace’ needs to have more within it and this happen through support of the voluntary sector to develop options etc.”

Supporting carers’ health and wellbeing

The *State of Caring* survey also found that 84% of carers surveyed said that caring has a negative impact on their health. Accessing quality, timely support can help to maintain a carer’s health and wellbeing, yet the study *Rest Assured* found that the barriers preventing carers from asking for help included a lack of appropriate provision, guilt and uncertainty about eligibility criteria.

Carers often become frustrated with trying to navigate their way through the system and drop out, only to re-emerge later when their needs become greater and they are in crisis. A duty to support carers would address some of these barriers meaning carers could access support at an earlier stage and potentially avoid crisis.

“Carers provide a vital service and, like the paid work force, should have rights and entitlements to enable them to continue to care this without risk to themselves”

“There are more demands placed on carers with more people being supported at home”

Enabling carers to challenge decisions

One of the frustrations carers experience at the moment is that when they are told there is no support available to them, there is no way for them to legally challenge this, as there is no statutory responsibility to support them. Many carers expressed the view that they would like 'to know where I stand' and be able to challenge decisions. A duty would begin to set out what carers can and can't expect in relation to available support

"They need to be held accountable."

Potential Unintended Consequences

While the majority of carers support the proposed duty and believed it would produce positive outcomes for them, there were still concerns that it has the potential to result in some negative impacts for carers. Most concerns centred on the development of the eligibility framework, the successful implementation of the duty and what resources would be available to support it.

Eligibility criteria may prevent carers getting a service

Carers were concerned that the eligibility to receive support may be set too high, meaning only carers in crisis would be able to access support.

"Who supports those who don't meet eligibility?"

"It is important that the eligibility framework is not placed at too high a level meaning many carers would be ineligible for support"

"It is good to know what you are entitled to - but as I said before, if the eligibility is set too high, people at risk of reaching breaking point in their own situation could be let down. Perception of the personal circumstances and the effect on day to day life is what matters."

"COULD MEAN PEOPLE LOSE OUT"

Locally developed eligibility criteria may result in huge variation

Carers were very keen that the legislation would reduce the inequality faced by carers across Scotland and lead to greater consistency in accessing support. However, they felt that if each local authority was responsible for developing their own eligibility criteria, this would not reduce inequality and there would still be the potential for massive inconsistencies within the system, with carers from one local authority able to access a much higher level of service than those in another. They were comfortable with the idea that each area may develop different types of support, according to local need, but were not persuaded that there should be variation in the eligibility criteria. This view was unanimous across all of our consultation events.

“A centralised (national) criteria is absolutely essential because it is currently disjointed resulting in unfair approaches in some areas. There should be a minimum offer of support so that nobody receives less than the minimum”

“Eligibility criteria must be national – don’t want people moving area to get a better service”

Eligibility criteria may not take into account the complexities of people’s caring roles and their life outside of caring

There was an understanding that developing eligibility criteria is a complex area, particularly for carers, who are a diverse group and whose caring roles are also extremely varied. There are many factors that would need to be considered.

One thing is clear; it would not be a simple case of using existing eligibility frameworks, such as those used for other care groups.

The Western Isles are considering introducing an eligibility framework for carers access to short breaks based on the same model for disabled people which categorises people into different risk categories based on the intensity of their caring role (Critical, Substantial, Moderate and Low) We believe this model is too narrowly defined. Any eligibility criteria needs to take into account the complex nature of caring, including:

- The intensity of the caring role
- The impact of the caring role on the carer
- Other factors outwith the caring role which impact on the carer’s life, such as other dependents, employment status etc.
- The carer’s health and wellbeing
- Additional risk factors such as the age of the carer and any progressive nature of the cared-for person’s condition

In addition it needs to take into account the carer’s willingness to care and their ability to have a life outside caring.

Carers were clear that they should play a central role in the development of an eligibility framework as they are the experts in knowing what factors can impact on a person’s life and contribute to them requiring support in their caring role. It is not as simple as looking at the number of hours caring or the intensity of the caring role.

“This needs to be very carefully considered - with input from people who know what it is like to be in the situation. It is also vital to be aware that people have different strengths - situations that one person can cope with could be beyond endurance for someone else and this has to be taken into account.”

“Any framework should be produced jointly with carers and be at 'National' level on just local which could lead once again to post code lottery support plans.”

“Carers should be on the group that drafts the eligibility criteria and that should also recommend who else should be members of the group.”

“Any eligibility criteria should be transparent and carers should be involved in agreeing them, reviewing their implementation and auditing the accruing evidence of efficacy.”

Carers may not be able to access their rights

Carers were on the whole enthusiastic about the introduction of legislation, but some were cynical about its successful implementation. There were concerns that even if the duty to support was introduced, it would not be acted on and local authorities would not be held to account. This same view was also expressed by workers within statutory services who said ‘It won’t happen even if carers get rights’

Much of the success of the legislation will also be dependent on staff knowing about it and carers being informed of it. There is definitely a need for staff training, with several carers expressing the view that this should be mandatory for all staff from statutory agencies.

“Where a duty is put in place, it is important LAs adhere to it. There needs to be sanctions for those who do not provide carers with their rights.”

“Concern that if cared for are unable to access services then it will be unlikely local authorities will be able to meet the needs of carers despite legislation being in place”

“Training is essential – Carer Awareness training should be mandatory for all NHS and local authority staff”

Could result in greater bureaucracy

Overall carers felt that a duty to support and clear eligibility criteria would cut down on bureaucracy and carers having to jump through hoops to receive support. However, some thought that it could have the opposite effect and result in greater bureaucracy, form filling and gatekeeping.

“Could become over engineered; too rigid, crisis management”

6. Short Breaks

The majority of carers who either attended a consultation event or responded to our online survey indicated that they supported the proposal to introduce a Duty on local authorities to provide and promote short breaks linked to an eligibility framework

95% of carers who responded to our survey gave a positive response to this proposal and at many of our consultation events 100% of participants said yes to the introduction of this proposal. (Coalition of Carers meeting, South West Glasgow, Alloa, and the Borders) At all the events over 90% of carers supported this proposal.

In relation to the proposal to impose a duty on local authorities to publish and promote a short breaks statement there was a similar response. 93% of people who responded to our survey supported it and over 95% of carers who attended consultation events also indicated that they supported this proposal.

“The duty to provide short breaks linked to a requirement to produce a statement of short breaks availability at last brings clarity for carers to an otherwise confused situation”

Why carers support the proposals around short breaks

Similar to the proposal to introduce a duty to support carers and young carers, the proposal to introduce specific duties in relation to short breaks was welcomed by carers and was seen to be an important step forward. Carers see the duty as a way of achieving greater consistency in accessing short break services, having firm information on what they are entitled to and encouraging a greater focus from local authorities in developing quality short break services which would address their individual needs.

One of the reasons that carers particularly welcome the proposals around short breaks is because of the difficulty carers have in accessing a short break service. The research report ‘Rest Assured’⁶ found that over half of survey respondents (57%) had not had a break from caring. Black and minority ethnic (BME) carers were less likely to have had a break than carers overall at 63%. A significant barrier was the difficulty carers experienced when engaging with statutory social services.

Carers at our consultation events cited various barriers to not being able to access a short break, including lack of information, ‘didn’t know about short breaks’ being told they weren’t eligible and there being no suitable provision available locally.

“Stop the endless waiting for a break, waiting for a person to leave to get their place”

“At present this is a postcode lottery”

“I had to kick, scream, shout to get what I have got, and even then I was told that these places were so hard to come by, and they are quite often kept for emergency cases. But my point was who is to say that I am not going to become an emergency case if I don’t get it?”

Carers who had been able to access a short break greatly valued it as ‘something to look forward to’ enabling them to ‘re-charge their batteries’ and as a life enhancing experience.

“Getting this in the last couple of years has made a huge difference to my husband and myself - a little bit of ‘breathing time’ is wonderful. It would have been much easier for my

⁶ Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

daughter to adjust to it if it had been offered earlier - but she now looks forward to her respite breaks after a shaky start.”

Short Break Statements

The proposal to introduce a duty on local authorities to publish and promote a short break statement was seen as a positive way of addressing the lack of available information on short break provision. This was also identified as an issue by carers who contributed to ‘Rest Assured’⁷ which found that not knowing how to access a short break was the most common barrier to receiving support (43%)

“Not enough clear promotion of short breaks is available, online or nothing is often the case and people still hear about services by word of mouth. Even when the local authorities provides or funds the service this is the case, definitely need to continue this provision and get a lot better at promoting it.”

“All local authorities should have a shared directory of all available breaks; there should be equitable cross-charging across all local authorities (i.e. a shared resource)”

“L.As should be aware of the opportunities that exist in their 'patch' and should clearly state where all forms of support, help and respite are available. They should actively seek to signpost carers to a Centre where the most appropriate form of support will be ascertained and the carer supported to access them”

Concerns around implementation

The concerns expressed by carers in relation to introducing a duty on local authorities to provide and promote short breaks and publish a short breaks statement, were broadly similar to those expressed in relation to the duty to support. They included concerns around the development of an eligibility framework, ensuring there are adequate resources for implementation, not undermining the ability for carers to access preventative services, ensuring processes are simple and easy to navigate and above all that carers are able to access any new rights.

“Definitely need more investment if short break to be a duty”

In addition there were particular concerns raised in relation to short break services.

The definition of short breaks

The term short breaks is a confusing one for many carers and is not descriptive of the many types of support which can be accessed. Many carers thought that it only referred to support for the person they cared for provided outside the home, lasting for a few days.

⁷ Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

Many carers explained that they required flexible services to accommodate their particular needs, so the definition of short breaks would need to be broad and this would need to be made clear in guidance. For example, carers in both the Borders and West Lothian said the only short breaks that worked for them was a joint break away in a facility that provided additional support by trained care workers. For other people, their requirements were different, such as a group of parent carers in Edinburgh looking after adults with autism. For them unfamiliar places or people caused anxiety to the people they cared for making many options unsuitable. Only support provided in the home by a familiar person had worked.

“Need to define short breaks – as broad as possible allowing for choice”

Being able to access appropriate support

This was again a recurring theme, with one carer stating:

“There is no point in having a duty if carers can’t get access to the type of break they need”

Rest Assured⁸ found that a key barrier uncovered through the focus groups and interviews was a lack of appropriate provision for the cared for person. In some cases, what was offered was unacceptable because it was of poor quality or because it was age-inappropriate, resulting in carers turning down

These findings were replicated in the 2013 ‘State of Caring Survey’ by Carers UK which found that 46% of carers had raised concerns about poor quality care services.

“Once we hit the adult services... massive problems there because although we were approved funding, there wasn’t anything to spend it on because there is nothing appropriate”

Strengthening the duty to provide carers and young carers with support

In order to avoid the unintended consequences described, the National Carer Organisations are suggesting the following additions to the legislation/regulations and guidance, to ensure that the proposed duties produce the positive outcomes intended.

- **Resources.** At every event we were asked what resources would go with the Bill or ‘How will this be paid for?’ In order for the duty to support carers and provide and promote short breaks to be successfully implemented, resources must be found and allocated to carer support, whether from existing budgets or through the allocation of additional resources. We propose that Joint Strategic Commissioning Plans should clearly outline what resources are available to support carers and that a percentage of available resource should be directed towards carer support.

⁸ Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

- **National eligibility criteria.** As previously stated we believe that the eligibility framework and eligibility criteria should be developed nationally and that it is essential that they are co-produced by carers
- **Preventative Support.** The introduction of an eligibility framework must not have a detrimental effect on the availability of preventative support. Eligibility criteria must take account of the need for preventative support. In addition local carers' strategies should also outline their plans for providing preventative support to carers.
- **Timescales.** Many carers have faced long delays in accessing an assessment and then having the support they require put in place. This causes stress and undermines the benefits of support. We believe there should be a maximum waiting time between carers meeting eligibility criteria and receiving support
- **Portability.** When carers move from one local area to another they face the daunting task of starting again from scratch in getting support put in place. This is counterproductive and a waste of resources. We propose that a carers entitlement to support should be transferred from one local authority to another when they move and should only be reviewed if their circumstances change
- **Definition of Short Breaks.** The guidance needs to include a clear definition of short breaks which should be as broad as possible, enabling carers to exert the maximum choice in relation to accessing a personalised service
- **Suitable Provision.** The success of these new duties for carers will be dependent on the quality of the services they are able to access. Carers need to be treated as equal partners and involved at a strategic planning level and in decisions around local strategic commissioning,
- **Sanctions.** We believe the duty to support carers would need to be carefully monitored and sanctions must be imposed on local authorities who fail to comply. The government should work with local authorities to monitor implementation and ensure compliance
- **Training.** If carer legislation is to be successfully implemented staff will need to be fully trained and aware of their new duties and responsibilities. Otherwise carers will still struggle to access support. Staff training in carer awareness should be mandatory and should build on the EPIC model.

7. Stages and transitions

Stages

Carers experience different challenges at different stages in their caring role, and recognising these challenges and planning for them (where possible) ensures that support provided to carers is appropriate and suitable. We agree that guidance for those agencies undertaking a Carer's Support Plan or Child's Plan will be beneficial for carers and ensure that changes in stages of caring are managed appropriately and where possible, planned for.

"All change is difficult to cope with and anything that can have planned transition intervention is to be welcomed. However it is also important to be able to react promptly to changes outwith transitional stages so that support is given when required most."

"The important thing is that carers should be involved in planning, implementation and management of such."

“They should also take account of the educational and employment requirements of carers and the effects of caring on costs, income, pensions etc.”

Carers agree that guidance on managing stages of caring should be developed for those undertaking the Carer’s Support Plan (or Child’s Plan) – 95% of respondents to the online questionnaire were in favour of the introduction of this guidance. Carers must be aware and informed of their right to request a review to their Carer’s Support Plan. However, sometimes a caring situation can change so quickly that relying on a Carer’s Support Plan to manage these changes and provide the right support will not always be quick enough to support the carer. The guidance must specify what the procedure is for emergencies or unexpected changes to the caring situation, when support needs to be put in place immediately, and local authorities must be prepared to deliver this kind of support.

[...] “we do need local, flexible action, personal autonomy, and fast access to professional accredited resources like residential respite in an emergency.”

“Carer support plan needs to be renewed regularly – there should be a duty to do this.”

“They have to be committed that the information will be used to support the carer and the service user.”

As discussed in detail on page 5, we would like to see a commitment to ensuring that emergency and anticipatory care planning is always included in a Carer’s Support Plan.

Transitions

Young carers who become adult carers can face significant challenges. Adult carer support services are not always suitable for young people, who may be put off if other carers they meet through peer support groups etc. are older or do not have similar caring situations or lifestyles. Young adult carer services that work with carers aged 18-25 are not universally available across Scotland, although there are many areas of good practice. Carers are overwhelmingly in favour of the proposal to put a Carer’s Support Plan in place for young carers before they reach 18.

“Young carers may not want to become adult carers so it is essential that they have the option. If the carer support plan is in place local authorities need to see what support if required for the service user in advance of any decision made.”

“Well before they are 18.”

Young carers who are likely to become adult carers should have a Carer’s Support Plan agreed 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. We would suggest that the plan is put in place at least 1-2 years before they are due to leave children and young people’s services.

“This should be implemented as a duty also or it will be the same scenario as transitions for young people reaching the age of 18. Nothing is done and when it is it’s too late.”

“I think YCs need support long before this so that they can make the most of their educational opportunities and not be swayed by those they care for into making decisions that will block their long term goals e.g. staying on at school, going away to university, taking employment away from home etc.”

“Continuous support should not be compromised.”

An initial assessment to ascertain whether a young carer will continue to care as an adult could begin even earlier, in line with transition planning for children with disabilities, which begins at age 14. Young carers who do not become known to social work services or young carer support services until after their 16th birthday should have a Carer Support Plan carried out as soon as possible, so the support will be available immediately as they become eligible for it.

Carer involvement in service design and delivery

Current involvement of carers in shaping services is patchy. In a survey of carers⁹, only a third felt that their involvement as equal partners in planning services in their area was good to excellent but a greater proportion, some half of respondents, said that their experience was poor or very poor. Even fewer (27%) felt their involvement in discussions about service changes was positive with 55% said that their experience was poor or very poor.

We therefore support the proposals to place a duty on 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. However, this involvement must be both meaningful and resourced.

“Provision should include: involvement of carers from a range of backgrounds – including “new carers”; affordable (free) and accessible opportunities to attend events; provision that reflects best practice standards for consultation with carers.”

“Carer involvement means talking and making sure carers are involved meaningfully in a way that benefits them.

“Recognise third sector as equal partners in integration and give them the status they deserve in partnerships at a strategic level.”

“Carers should be given training, support, briefings to help them contribute effectively.”

We also believe that young carers should also have an opportunity to be involved in shaping services in their community. This can be done using methods which are age appropriate and in partnership with young carer support projects, such as local young carers forums and the Scottish Young Carers Festival.

⁹ Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

Involvement of carers in the development of carers' strategies was also reported to be patchy. Only 26% of carers in our survey¹⁰ felt that their involvement was good to excellent (5% said it was excellent.) 19% said it was acceptable. More than half (55%) said that their experience was poor or very poor.

Local carers' strategies are currently developed by some local authorities to set out what their plans are to support carers and develop services in their local area. These local strategies do take the national carers' strategy into account, but there is a lot of variance in local priorities and this can lead to services in some areas being very different to those available in other areas.

We support the Scottish Government proposal to ensure that carers are involved and believe there should be a duty on local authorities and health boards to involve and collaborate with carers and carers organisations in the development of local carers' strategies. These should be connected to the national carers' strategy.

We believe that young carers' strategies should also be developed. This could be a distinct part of the carers' strategy or a separate document but must ensure that the needs of young carers are considered alongside adult carers in the local area. Not all young carers will be accessing children's services and therefore may not be covered by a Children's Services Plan.

Again, carer and young carer involvement in the development of carers' and young carers' strategies must be meaningful and adequately resourced.

"Carers organisations can represent carers. They can represent a range of views. Need a range of organisations, not just national organisations, need local knowledge."

"Young carers need to be included at a formal and strategic level of local planning not just the informal routes of forums and Facebook Groups."

We believe that local authorities should also be required to 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' centres and services. This would be the minimum standard for services to provide for carers. Existing carers' services should be supported and resourced.

8. Carer involvement in care planning and support

Carers should have the right to play an equal and active role in care planning and decisions, with the consent of the individual. The principles of the Social Care (Self Directed Support) Scotland Act 2013 also reinforce the full involvement of carers in the assessment of needs for support for the person they care for and in the provision of support for themselves. Other existing legislation requires that local authorities take account of the views of carers in the assessment of adults and children before reaching decisions on what services or support to provide. This is to ensure that the care package meets the outcomes for the service user and the wishes and needs of both the carer and cared for person, as far as possible.

¹⁰ ibid

We support the Scottish Government proposal to enhance legislation to ensure that carers are involved 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. Our experience shows us that current practice can differ widely both within and outwith local authority areas. Too often, the level of involvement afforded to a carer is dependent upon the actions of an individual practitioner. We believe that a Duty to ensure carer involvement in care planning will address variations and inconsistencies in local practice.

In a recent survey of carers in developing the Carers Rights Charter¹¹, only a third of carers knew they had a right to be treated as an equal partner and just the same proportion were fully involved in care planning.

Carers reported that in some settings their experience was more positive, for example, in working with their GP, where more than half said that their experience of being treated as an equal partner in care planning was good or excellent. However, their experiences of partnership with other professionals were less positive. For example, there were significant levels of carers saying that their experience of partnership has been poor or very poor in hospitals (45%) and in care assessments (33%).

“GP is happy for me to attend appointments with my mother & explains treatments, medication etc. to me.”

“I would pass on my observations / opinions to the district nurses attending my parents. This was either ignored or viewed as an irritation. Case in point; I expressed concern over the increasing discolouration of my mother's toes over many weeks. The nurses insisted there was no cause for concern. I insisted on calling a doctor - against the advice of the nurses. This resulted in my mother being admitted to a vascular ward in ERI, having two angioplasty procedures & three toes amputated. She was never discharged from hospital as she died four weeks after admission.”

“I constantly feel that Social Work are not listening to what I am saying about my father.”

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. We also support the proposal that this principle is extended to young carers.

“Carers should have a right to be treated as an equal partner as they are the (safety) pin that holds the rest together.”

“Carers are the ones with the expert knowledge of the cared-for persons. We need tangible evidence that what we say is what they do!”

¹¹ Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

“It should be a legal requirement for carers to be involved and for their needs to be addressed.”

“It is crucial for carers to be involved when decisions will impact them as well”

9. Carer identification

Identification of carers remains a challenge despite a wide range of initiatives designed to improve this. GPs are in a unique position to be able to identify carers who may be attending the practice to support the person they look after as well as attending for their own health needs, and therefore GPs and allied health professionals are perhaps the best placed people to identify carers at any stage in the caring journey. However, identification of carers through GP practices remains inconsistent across Scotland and there is limited evidence to suggest that GPs actively seek to identify carers they come into contact with.

The requirement to identify and refer carers was transferred into the core element of the GP contract in recent years, but, the contract does not specifically mention a carers’ register. GP practices currently apply a code to an individual’s medical record within the practice if they are identified as a carer; collectively, this information can be used as the basis of a carers’ register. Whilst there are pockets of good practice within individual GP practices, more stringent measures must be taken to ensure that all practices comply fully with the contractual arrangements, particularly as they receive funding for this through the GP contract.

The majority of carers (75%) who took part in the online questionnaire felt that both local authorities and GPs should have a duty placed on them to identify carers. 17% of respondents thought that only GPs should have a duty placed on them, and only 5% of carers thought that the local authority alone should have a duty placed on them to develop and maintain a carers’ register.

“GPs have knowledge of the people who are in a caring situation within a family and would be ideally placed to check with an individual that they are aware of the ability to have their caring needs met and supported. However, with 35 years of caring behind me, I was never approached about my daughter’s care needs since I had always just managed things on my own. Even when we were forced to look for medical interventions to try to help with my daughter’s emotional and behavioural problems worsening in the home, no support was ever suggested and we were never asked if we were getting any outside help (which we weren’t!) This means that more stringent measures would need to be put in place.”

“Important for things as basic as eligibility for flu jab etc. Helps GPs to be aware of stress and strain on individual patients.”

“This should not be the responsibility of a GP... The Government and Local Authorities should do the job we pay them for... GPs do enough already.”

“GPs should be able to alert via their contact with carers. They will in many cases have more contact than social work. However joint plans should be produced with new proposed integrated services.”

There should be a legislative requirement for GP practices to develop a register of carers within their practice. The coding mechanism is already in place to enable a register to be created, but we think that there is limited value in creating a register if it is simply data collection. In addition to the identification of carers, GPs should be required to proactively refer carers for assessment, which should also be recorded on the individual patient record. The carers' register should trigger an offer of an appointment for the individual carer every six months to determine if the caring situation has changed and whether additional support is required in terms of the carer's own health and wellbeing. There is currently some good practice in the provision of health checks for carers, and this should be implemented more widely. A legislative requirement to identify carers would help with this.

"There should also be a requirement to not only hold a register but to use it to alert Carers Centres to new carers, carers who are struggling etc.

"There should be a clear purpose for the register. These will include talking to the carer, signposting the carer to services outwith the practice, providing health checks for carers and keeping the signposting going as any changes in the carer's health or wellbeing shows itself. Carers will listen to GPs and if they recommend going to the local carer's centre, they'll go."

We see less value in placing the same requirement on local authorities as many carers may never come into contact with social work services. Where carers are in touch with their local social work offices, their details will be available on internal client recording systems either in their own right via a carer's assessment or on the community care assessment of the person they are providing care for (subject to changes proposed in this consultation paper regarding Carer's Support Plans.) The forthcoming integration of health and social care will provide an opportunity to develop integrated ICT systems to enable the sharing of information across GP practices and local authority social work departments. Many carers who took part in consultations felt that this would maximise the reach of a carers' register.

"All voluntary and statutory organisations should be responsible to identify carers."

"There should be a duty [on] all health boards, LAs and voluntary sector to hold and share carers' register."

GPs should be required to report annually to their respective Health Boards on compliance with the GP contract. We also agree that Health Boards should, in turn, be required to report on compliance to the Scottish Government. Reporting should include the number of carers identified within the practice, how many carers have been referred for an assessment, and how many 6 monthly reviews have been undertaken. To support this and provide a focus for carer identification and support, the appointment of a carers lead within individual practices would be beneficial.

Carers are mostly in favour of placing a duty on health boards to monitor compliance with the requirement to hold a GP register. Some wondered whether this would have any real effect on the carer.

"No point having a register [if] it is not closely monitored."

“There should be a lead person within each GP practice to ensure compliance with the GP contract.”

“No point in placing a duty of care on them if you don’t ensure that it’s followed through.”

“In my local practice, which has 9,000 patients registered, the carers’ register has 38 names on it. 1:8 people are carers – I rest my case.”

Slightly more carers were in favour of the promotion of good practice amongst health boards. However, we believe this will only be effective if it is combined with the duty on health boards.

“It may be more helpful to provide guidelines on what to do with the carers’ register – its use, purpose, value, cost-effectiveness to the NHS etc etc. Advising carers to use their local carers’ centre would be a simple and effective step for all carers. That raises awareness of the carer that they are a carer and that the centre is there to support them throughout their caring role.”

“There is an over reliance on ‘sharing good practice’ without ensuring that it is incorporated within each local authority.”

“Health professionals already overstretched in the community.”

Good practice can be incorporated with guidance and other materials to support all agencies that are identifying carers.

10. Additional Proposals: Hospital discharge

Spending time in hospital, either due to an emergency or a planned admission is often a time of concern and additional stress for both carers and the people they care for. This is consistently the case, both when it is the carer who is admitted to hospital and when it is the person they care for.

An admission to hospital often results in a person becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs.

Where a carer requires hospital treatment this frequently means they are unable to continue to provide care while they recover, or sometimes, due to ongoing ill-health they may no longer be able to continue their caring role or may have to re-evaluate the level of care they can provide

It is therefore essential that at these times carers have access to information and support, from the point of admission to discharge and that their views are fully taken into account when the discharge plan is put in place.

“Carer support should be a part of hospital discharge planning and it should be available on discharge where appropriate.”

Best practice example: Stirling Carers Centre employs two Carer Support Officers based within the Allied Health Professional team at their local hospital. They work in partnership with NHS professionals to identify hidden carers at all stages of their hospital journey, helping them to navigate their way through the system from admission to discharge. The Carer Support Officers work with carers to enable them to be equal partners in care and therefore play an active role in the discharge planning process. This ensures that the patients and their carers leave hospital with the appropriate support in place to retain as much independence as possible in their communities.

Best practice example: MECOPP employ two Hospital Discharge Support Workers through Change Fund monies to provide dedicated support to BME older carers and those in receipt of care who are admitted to hospital. The purpose of the project is to: identify those who come into contact with acute healthcare services; support them to actively participate in the hospital discharge process; ensure they are referred to appropriate support agencies; and, are supported to remain within the home/community setting. The project works in partnership with a similar initiative provided by the City of Edinburgh Council and NHS Lothian.

Carers’ experience of Hospital Discharge Procedures

A recent survey undertaken by Carers Scotland and MECOPP in relation to the Carers Rights Charter asked carers about their experiences when the person they cared for was in hospital. On both admission and discharge, dissatisfaction was high. At these key points, where carers' knowledge and experience of the person they care for is vital, very few carers feel they are treated as key partners. 39% said their experience was poor or very poor on admission and 45% at hospital discharge.

“I would pass on my observations / opinions to the district nurses attending my parents. This was either ignored or viewed as an irritation. Case in point; I expressed concern over the increasing discolouration of my mother's toes over many weeks. The nurses insisted there was no cause for concern. I insisted on calling a doctor - against the advice of the nurses. This resulted in my mother being admitted to a vascular ward in ERI, having two angioplasty procedures & three toes amputated. She was never discharged from hospital as she died four weeks after admission.” (Carer, Carers Rights Charter Survey)

“My biggest problems have been at time of hospital discharge over the past three years which have caused quite a bit of unnecessary stress following long periods of hospitalisation. A lot of it was due to poor communication and lack of attention to detail. I would say that in 5 out of 6 discharges I was definitely not an equal partner and once I was made to feel that I was a nuisance! I was really upset at the time but was too tired to go

through the complaints procedure and so let it pass although I know I should have taken action.” (Carer, Carers Rights Charter Survey)

“I am so worried when the nurse tell me I am ready to leave hospital soon because I live alone and I may not have the appropriate service or equipment when I go home. However, MECOPP help me to get access to additional equipment, and also help to organize the care at home package for me so I will have the service when I go home in the next few days. It really gives me peace and I look forward to going home.” (Chinese older person)¹²

“It makes our work so much easier after talking to the family with help of the HDSS support worker because we know what exactly the family concerns and preference of for care are and we can start to arrange the care package for the patient.” (Nurse in Liberton Hospital Ward 2)¹³

Often when people are anxious to leave hospital they do not consider the additional support they will need when they are at home and the impact this will have on their primary carer and other family members. Taking the carer’s views into account is key to ensuring that appropriate support is put in place, avoiding the risk of additional stress and carer strain.

“Nobody listens to the carer’s advice when hospitals, rightly or wrongly, decide whether or not to send the cared for person home. This has to change.” (Carer, North Lanarkshire)

Poor discharge planning may also result in the person being re-admitted to hospital. The State of Caring Survey by Carers UK found that 37% of carers said that the person they care for was discharged from hospital too early because either support was not available or they were not ready to come home and 18% of carers surveyed reported that the person they care for had to go back into hospital within one month of being discharged because their health had deteriorated again and 8% within two months.

“My mum was discharged from hospital medical ward because she had onset dementia. I had my concerns about her going home to live alone and the hospital Social Work Department were unsympathetic. 4 weeks later my mum was re-admitted to hospital and is going through all of the same process as before. I have great concerns about her being discharged home again and I feel bullied by Social Work.”

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. There should not be a presumption that family members will be available to step in and provide care on an ongoing basis. Planning needs to take account of the complexities of people’s lives, such as their employment status, other responsibilities such as dependents and additional caring roles, their age and their own health and wellbeing. Unless carers are fully involved in discharge planning a full picture of what resources are required will not be achieved

¹² Innovation Fund Progress Report MECOPP 2013

¹³ Ibid

“I feel the carer should be consulted more. My father said he was ready to go home so he was discharged... I had to take 2 weeks off work to care for him full time.”¹⁴

“I work full time as well as taking care of my husband who has MS. When he recently left hospital, I was not asked about the impact this would have on us, what help we had in place or if he would be able to manage in our home. He had to sleep on the sofa for 3 weeks following his release and had many bathroom accidents as both the bedroom and bathroom is upstairs and he cannot reach them. Very stressful for both of us”¹⁵

When carers are also patients

Where carers are admitted to hospital their discharge plan needs to take into account replacement care to ensure they are not having to provide care which may be physically or emotionally demanding while they are recovering.

“Hospital discharge planning needs to include replacement care planning to ensure carers do not compromise their own recovery”

At our consultation events, there were several examples provided of carers who were forced to go back to their caring role before they were fit to do so, because there was no replacement care available. One person who had suffered several aneurysms was only able to arrange a few weeks care from an elderly relative in their nineties to support her husband. She then had to resume her caring role as her local authority failed to provide her with any support.

Another carer was advised he should take three weeks off from his caring role, following an operation, but his local authority only provided support for one week.

Research by Carers UK has also found that often carers delay medical treatment, including operations because of concerns about who will replace the care they provide.

“I became ill overnight. I was haemorrhaging internally and needed immediate hospital admission. I called social services emergency line. In short it took 10 hours to get adequate help organised before I could get myself to hospital. The consultant said I was lucky not to have died”¹⁶

Even in cases where carers are able to access replacement care while they recover, this is sometimes taken from their existing short break allocation, with one carer who was in hospital on a drip being told: *“you’ve had your six weeks respite break this year”¹⁷*

Proposal for a Duty on hospital admission and discharge procedures

Despite the existing Scottish Government protocol on hospital discharge, practice across Scotland differs widely and very often is to the detriment of carers. We strongly advocate that

¹⁴ State of Caring Survey, Carers UK, 2013

¹⁵ Ibid.

¹⁶ Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

¹⁷ Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

hospital discharge must begin at the point of admission with the full and active involvement of carers. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration. Discharge planning must take account of the level of care that carers are willing and able to provide and should put in place additional support or replacement care where required.

We therefore propose a **duty on health to inform and involve carers in hospital admission and discharge procedures.**

The National Carer Organisations

April 2014