

# SUMMARY OF RESPONSES TO NATIONAL CARERS ORGANISATIONS' SURVEY ON THE CONSULTATION ON PROPOSED CARERS LEGISLATION

## CARERS ASSESSMENTS (CARER SUPPORT PLANS)

Question	Yes (%)	No (%)
1. Do you agree with changing the name of a Carers Assessment to a Carer Support Plan?	86%	14%
2. Should there be a duty on local authorities to offer all carers a Carer Support Plan?	99%	1%

### Comments

- I was a regular and substantial carer for many years but was never aware that I was entitled to support or respite until recently
- I am a foster carer and have been refused a carers assessment
- If not their duty it won't happen.
- Of course there should - how else will the LAs know what we need. Mind you - it'll have to have teeth and help get carers the help they badly need
- Not everyone will seek support but I believe it should be offered or available.
- If a document is given to the carer to complete they should at signposted to their Carers Centre for help to complete the form. Carers Centre's will have to be funded to provide this help.
- There is already a statutory right for all carers to receive a carers assessment - if the carer so wishes.. It is the only legal right we have and has been around for many years. Change the name to whatever is not going to change his. Getting local authorities to actually DO anything with this assessment is the problem. All too often the assessment is marked; no service available'.
- It would allow the carer to perhaps get assistance, equipment for the person they care for and support. As carers get older they may not be able to cope as they did. Finances can be a problem for a carer with the cost of living going up, changes in benefits perhaps this would be an avenue for information to be given.
- But prevention must remain at the heart of Carer Support Plans and eligibility criteria must reflect that so that councils do not default to crisis only intervention or set the eligibility framework so high that only carers in desperate situations get a Support Plan completed. If it is the CSP is not seen as a major step in preventing carers from failing to cope then it should not be brought in as a duty.
- Only way in which you can address the required "prevention" agenda

- They should have the right to get offered one and the right to refuse it
- Monies given to Local Authorities should be ring fenced for the Carers Support Plan.
- I am a full time carer for my wife, it's very hard work but I'm not complaining about that. What annoys me is forms that class me as unemployed.
- Identification of a carer is crucial for their entry to the systems that will support them. As we have no idea how much care carers will provide from day 1 due to the nature of the medical condition(s) of the cared-for, it should be the duty of both NHS and L.As to be aware of carers and to provide information from the first point of contact.
- Yes, carers provide an essential role which not only supports the person they care for but they can also be carrying a large burden on their shoulders which would otherwise fall to the LA's.
- Previous Carers 'Assessments' in West Lothian felt more like an examination of the Carers Competence and ability to Care. I never felt it was supportive.
- I agree that carers have to be recognised fully but as A CPN we are already expected to care manage and this is another piece of work (support plan) we will probably be expected to complete. We are already stretched and are struggling to even carry out our work as CPNs due to other social issues we are expected to do. Our core work as Psychiatric Nurses is being eroded over time and patients will suffer. Carers support plans really should be completed by staff at the Carers Centres to allow professionals like ourselves to concentrate in other aspects of care.
- Not all carers know of the "carers assessment" nor do some social workers .Older carers caring for an older husband or parents should be given priority
- But also to follow up on the status and well being of all carers
- It is fundamental to maintaining the well being of the family unit, and SAVES money.
- What annoys me is the prying into all your financial circumstances.
- All carers roles, ages, circumstances, financial means and environment are different therefore each and every carer needs a tailored support plan.
- WOULD BE NICE IF I COULD GET A DAY OFF INSTEAD OF 24/7
- There is not a lot of point for there to be a duty to offer a support plan if there is not also a duty to give carers the services they have been assessed as needing. Its pointless marking us down as "unmet need" as has happened to my husband and I.
- This support plan's agenda should have carers at the centre and not just be another tick-box exercise where statutory agencies say they've engaged with carers, get them to fill in a 60 page form then do nothing for them, whatsoever. As was my experience in 2012 in Fife
- Perhaps only if the carers request one but they should all be asked when they become carers and reviewed after a 2/3 years.
- However, this duty to offer must be coupled with a duty to deliver the services required to meet the needs identified. Where those needs can't be met - given current resource restraints - this 'unmet

need' must be identified as such so that the duties and provision of of the support plans meaningfully contribute to long term planning and commissioning. otherwise pretty pointless!

- As long as the plan is of real value, otherwise just more needless frustrating bureaucracy.
- Lack of information regarding entitlement to support resources is woeful - most of my knowledge has been gleaned from other carers. Six years into my husband terminal illness I have only just been informed that I'm entitled to 6 weeks council funded respite care a year. I often feel that no one will give me a straight answer to my question and that despite being involved with multiple health professionals that there is little communication between them.
- They should also agree a time frame and not have people waiting weeks
- I agree but Mental Health should be acknowledged in a separate Support/Assessment pan as the circumstances surrounding M.H. is totally different then generic caring
- I think there should be a dedicated appropriate time limit for this.
- And the plan should be adhered to, anything that is recommended should then be guaranteed.
- Carers should also be offered an individual budget
- It is important to remove 'the regular and substantial test' and extend the Carers Support Plan to all carers. This will mean early identification and should help more carers receive appropriate support. The support plan should be based on the carers needs and should be regularly up dated to ensure that as young people and their carers grow older plans continue to meet needs. It is essential that cares are given support to have lives outside of their caring duties.
- Its absolutely imperative that the carer's needs have to be acknowledged and prioritised In order for them to fulfill their be caring role
- It should not be left to Glasgow City Council's discretion
- Carers Assessments are not acted upon at present as the guidelines are not clear to Local Authorities
- Being 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.
- I don't think it matters much what the plan is called. All carers should be entitled to an assessment of their needs, hopes and aspirations, if this is what they want. Local authorities, health boards and vol orgs should promote, and do all they can to identify carers. Not every carer will come forward though, some won't need support, but they must know that support will be there if/when they need it.

Question	Yes (%)	No (%)
3. Can you see any drawbacks to widening eligibility to all carers?	31%	69 %

## Comments

- It may be difficult to inform people like me who are not aware of their entitlements - and widening the eligibility will put demands on the services
- I feel the term 'carer' needs to be very clear.
- There will be more workload.
- In current times of austerity, those with the highest levels of need could lose out
- Why would this be regarded as a drawback???? There are many different reasons why someone is a carer - could be children with disabilities, kinship carers, looking after grandchildren, looking after adult siblings or parents. One size does not fit all
- Although be careful not to lose focus of targeting carers needs
- Each assessed on their own specific needs.
- You can include as many carers as you like - the answer is still the same. We get nowt.
- There are carers who are not recognised and may not be aware of these changes how do we get this information to them. Will there be enough staff to cope with the volume of carers social services are at a premium support to carers are the same. Care in the community is at breaking point there are not enough paid carers, community nurses, criteria for what a carer and service user can have.
- As above, demand on councils and how they handle it.
- Costs will be recouped over time by identifying carers, reviewing their needs and preventing expensive interventions
- Demand for support plan may result in capacity issues/time delays etc.
- All Carers should be offered the support plan regardless of their caring situation. It maybe that they do not need a plan but should still be offered.
- Social work depts may not be able to cope with the numbers involved and resources required defining it, implementing it in resource terms
- As health and care professionals will be aware from point of first contact, it will be easy for NHS staff to identify carers who will need ongoing support and an assessment will be the start of the journey for unpaid carers.
- It can only be a positive step for carers and for those they care for.
- Again as stated above, who completes these plans. I can see it falling on already overstretched professionals instead of the carer centres.
- Councils do have enough money to support all carers
- No, not at all. The carers who do not shout for help are often the ones who may need assistance.

- It would prevent many carers reaching crisis point, saving local authorities money and better quality care as carers will be better supported.
- Yes costs to local governments
- There may be carers currently without any support plan who are struggling in their role and would benefit from a support plan.
- Those of us with very heavy end caring responsibilities (24/7 in our case) can't get our needs met as it is - it will be even harder if you widen eligibility.
- However, be careful not to lose focus of targeting carers needs - widening out risks, losing direction and focus on effective support
- Financial constraints. I have already seen the impact of financial constraints within my local authority in terms of care planning, availability of short break funding and also aids & adaptations.
- Because all unpaid carers should be supported in their caring role. It makes sense and will be more cost effective in the long term. Buying in care from private agencies is fraught with difficulties, especially when the bulk of the money goes to the care agency rather than to the care worker.
- There could be insufficient resources to support carers
- As long as there is a recognised continuum of carer need - identified by the carers - not through a process of value judgement based eligibility criteria.
- Lack of identifying all carers, making sure there is adequate resourcing involved.
- Insufficient resources provided to enable this to be implemented.
- More people requiring the same limited resources.
- The Drawbacks are Government made to slow the process
- As above you have to differentiate from generic and mental health care.
- Money
- At present we may not be doing an official assessment of the carers but we are dealing with their needs anyway so I think it would be a good idea to do a support plan for every carer
- Councils will not offer to all because of costs- they don't now - funding from Scottish Government to local councils to provide respite breaks for carers monies should be ring fenced - councils currently spend that on whatever because it is not ring fenced.
- There will obviously be concern that support plans will take even longer to complete and services to some carers could be diluted if there are not enough resources to fund identified plans.
- There just isn't enough services to cope with the number of people in caring roles
- The system in place would require a re-design

- Yes increased expectation and the inevitable disappointment when there's a lack of adequate delivery due to economic/budgetary constraints.
- Those who are most in need struggle currently to access support what chance will they have now
- Longer waiting lists unless additional social workers allocated to do this
- It makes good economic sense...and not all carers will need/want access to a plan/assessment.
- I am one of six siblings - all in our 60's or late 50's supporting my two frail elderly parents in their 90's on a rota basis: none of us care for more than 35 hours a week, and yet our caring situation is highly complex as we are scattered right across the UK. It is also important to realise that - post Independence - many families will be caring across not only local authority boundaries, but also a national frontier. By the way, I also care for my son, who has a learning disability. It is a juggling act.

Question	Yes (%)	No (%)
4. Do you think statutory guidance on the content of Carer Support Plans is sufficient?	85%	15%
5. Do you agree with the proposal to have different levels/depths of Carer Support Plans?	89%	11%

#### Comments

- 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
- This is essential as the levels vary greatly
- Ok - I do agree with the proposal, but I want to have you hear my say - it's a bit like the ASL bill several years ago - it noted that a lot of kids have additional needs, some short term, some long term and again, the one size fits all wasn't working
- Each carers and the person they care for already have different needs and this should be taken into account when assessing. If you start putting this in writing assessments will be followed to those guidelines. Each case should be looked at as individuals.
- Each Carers Role is different, with different needs and help required, the support plan should be meet the needs of the carer and the cared for person so it should be a unique to their needs.
- Because these things vary, and it also depends on the context of the carer's other commitments
- It should be a sliding scale dependant on the amount of care needed
- Yes, depending on the level of cares capacity to care and their requirements.

- No need to legislate for that if all Carer Support Plans are centred on individual circumstances and needs. Let's have equal respect for all please.
- Who would decide the levels/depths?
- Some people require much more care than others my child has cp and requires 24 hr care
- IT SHOULD BE THE SAME FOR EVERYONE
- Again it makes sense to give more support to carers who are giving more support to the person they care for, whether that person has physical, mental or learning disability health issues.
- Carers don't need the same level of support especially in the area of mental health. When the person cared for is well carer support does not need to be so great.
- Everyone should be assessed in the same way and reassessed as the situation changes.
- I think the level need to on an even keel so that people get the right help without being past from pillar to post
- Different people have different needs and varying expectations.
- This sounds like means testing
- If the Individual needs warrant different levels
- As long as it isn't based on earnings. All Carers should have equality regardless whether homeowner or not
- Yes in principal but i would need to see what it looks like.
- Depending on how much time they spend caring for a relative. If they do not live with the person they care for they should not have the same level of support as a carer who looks after a relative 24/7
- Every person cared for is an individual therefore the needs are different
- I think this mirrors better the complexity of our lives and needs.

Question	Yes (%)	No (%)
6. If not, do you think that the Government should legislate to provide a minimum standard for issues to be considered in the Carer Support Plans?	96%	4%
7. Do you agree in removing the need for the person you care for to be receiving community care or children's services?	51%	49%

## Comments

- My daughter is 35 and I had always just 'coped' and met all of her needs myself. It was only a couple of years ago, when trying to plan for her future, that I approached Social Work. This was when I found out that we could have been getting respite services which would have made our lives much easier. We had never been receiving care but we did need the assessments to gain support.
- If the carer for refuses help or cannot access help then the carer needs still to have an assessment in their own right.
- Not entirely sure I understand this question. If you are suggesting that unpaid carers do all the caring for someone with complex needs then this is ridiculous. We need support.
- I do not have community care. The area in which I live has problems in employing carers and respite care is at a premium. I did have a carer for half an hour for 4 weeks last year after major back surgery in fact we had 15 different carers my sister supported me more than the community.
- Many older people in particular refuse services even though the families are desperate for support.
- A way of addressing and including the many hidden carers
- Being a carer or cared-for person brings with it a number of issues that can't always be quantified. We know that relationships are affected, that the cared-for can become either anxious or depressed and be frightened for the carer to leave. Please be aware that everyone is different be they carer or cared-for.
- At the moment my husband does not require community care, however this may be needed in the future
- It would be very 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.
- No, community care and services are scarce enough. Carers need more support than ever and cutbacks and changes are making the caring role much harder.
- Many carers need support due to ill health, age etc and the cared for sometimes refuses services they need. These carers need more support.
- Opening up the remit wider would, potentially, lead to false claims. If you need support you need to be at least acknowledged by social work.
- However this is because my adult son, who I care for, got no support anyway from community care or social work services. I completed a carer assessment form and got nothing in response, and neither did my son. A complete waste of time.
- By linking access to a plan to existing receipt of a service this excludes people who have chosen not to receive a service (for range of reasons), people not receiving because the (often arbitrary thresholds of eligibility have not been met)
- If someone is caring for someone they need all the help they can get
- In Glasgow, children have no input from SWS and no funding for services. The criteria for these is restricted to children at risk. There are many Carers not known to SWS.



- This is very important as at present very few children receive any community services or support from social work children's services. Carers need a life outside caring and their children will require more input as they grow. Also many carers wish to continue working but cannot do this without an adequate carers support plan.
- There has to be some criteria for access
- Yes, it shouldn't matter that those you care for don't receive 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.
- Some people just refuse services, and that's their perfect right. But it doesn't make the carers life any easier.

Question	Yes (%)	No (%)
8. Do you agree with removing the assessment of the carer's ABILITY to provide care?	96%	4%

#### Comments

- Carers will perform to the best of their ability.
- No - because the carer often does not want to give the amount of care they often have to give. You have to assess how best the care can be given and how able the carer is to give it
- Yes carer is expected to care regardless of their ability
- Some carers still have not had an assessment, never been asked but continue to carry out the role
- Carers have to be as fit and able as possible.
- Carers can chose whether they have an assessment and are those making the assessment going to judge my ability to provide that care> If it is deemed that i am not suitable to look after my loved one - what will happen? Stick him in a home? No chance.
- There are pros and cons with this question. There can be issues with the carer feeling that the person they care for could be taken away from them on the other hand they may not be able to look after to the decrement of their own health
- This should be viewed in the light of a conversation not someone's personal judgement in a short space of time
- Not sure - can see arguments for both - perhaps it could be a decision made by a family group with care team

- I would however, like to be reassured that if I'm old and frail, I won't be left to move and handle my son. 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.
- No, it is very important for this assessment to take place to ensure the carer can cope and receive the correct support they require as well as ensuring they meet caring standards.
- That's not for bureaucracy to determine. Families want who they want and trust and Government should do all they can to respect and support the choices of the people who are being cared for.
- Some carers have different levels of ability to care.
- In some cases the "carer" can be in need of more support than the cared for, and quite often fall ill themselves( as has happened to my self)
- In some cases a partner or spouse may try and look after a loved one themselves but in some cases this is impossible to do i.e. because of age or disability or maybe they are not fit enough themselves. I don't think that some people know what help is available in their area or how to get it.
- Some people think they can manage, but as the cared for gets worse the carer may not realise the amount of care required particularly if it is a gradual decline.
- Some find this offensive.
- Depending again on age circumstances of carer and their own health there may be times they are unable to provide adequate care and temporary assistance may be required.
- Carers still have not had assessment, never been asked but continue to carry out the role
- Not sure what this entails
- Some carers still have not had an assessment, never been asked but continue to carry out the role.
- The carer themselves will be the judge of whether they have the ability to care and if not I'm sure they will seek the necessary help
- In order to care you need the person to be up to the job but if they need help and guidance to help them they should get it in order for them to do the carers role
- People who are ill do not always want the care provided by the system and prefer to have family and friends around them. Again this sounds like means testing
- May lead to inappropriate levels of care.2
- And so provide care through social services if the carer is not able to do so
- This becomes moral blackmail and carers are often continuing to give massive input even though they can no longer cope. It also results in poor family interaction as neither carer nor young person has any life outside their home. This will depend on the level of input each carer has with their young person/ adult.

- The caring role can impact and take its toll on the carer therefore it's important to assess to evaluate the current situation
- Willingness to continue caring perhaps
- No...the carer may feel they are able to care but they may themselves be frail, elderly or not be well enough to care at a particular time. Many carers continue to care at times with great risk to themselves. An external assessment may flag this up and ensure that both carer and cared for get help when they need it. Maintaining an assessment of ability to care may also have a preventative role and prevent a crisis situation from developing.
- This is a contentious issue: some carers have learning disabilities etc and need extra help: this must be taken into account surely?

Question	Yes (%)	No (%)
9. If you live in a different local authority to the person you provide care for, which local authority do you think should carry out your Carer Support Plan (Carers Assessment)	Narrative answers...see comments below	Narrative answers...see comments below

Of those who said either carer/cared for local authority, there was a roughly 50/50 split between the carer's local authority and that of the cared for people. However a proportion of carers said that it should be a joint effort with others saying that it should be the carer's choice. One carer highlighted the fact that some carers will be caring for more than one person in more than one local authority.

#### Comments

- The needs of the carer and the cared for person are separate. Your own local authority should carry out your assessment for support.
- The authority where the carer lives should carry out the support plan. This is where they pay their council tax for services to the carer.
- Carer's local authority with close links to person cared for.
- The LA in which the carer lives and taking account of their travelling time
- A joint assessment should be done between authorities with one lead person to ensure continuity of care.
- Should be a joint effort. Communicating with each other. For those bods in the ivory towers this means talking and listening to each other, emailing and writing and acting on info
- carers should have the right but be able to decide themselves or get support or advice if they need it
- It should be a joint process between both LA's.

- Authority where the person being cared for lives for easier tie in with other local authority services. Carer's local authority, where different, can be notified.
- I care for two sons, one of whom lives in a different local authority area. The Carer support plan should be undertaken in the health board area where the person who is cared for lives.
- Think this should be determined by the individual carer as there will be unique factors to take into account
- Does not really matter as long as that care assessment is done fairly.
- All local authorities should carry out local assessments but the assessment questions should basically similar but take into account the area the caring is being carried out i.e. rural areas

## INFORMATION AND ADVICE PROVIDED TO CARERS

Question	Yes (%)	No (%)
10. Should there be a duty on local authorities to establish and maintain a service for providing carers with information and advice on their rights, support, and access to a Carer Support Plan?	100%	0%

### Comments

- Carers are expected to be 'experts' in the care of their family member so training appropriate to needs should be offered and funded.
- If you don't know what questions to ask or who to go to for information, you could be missing out on valuable knowledge about changes that could be important to you and the person you care for.
- I cannot get any information from anyone regarding my rights as a carer as I am not his biological mother but his long term foster carer...but his needs are such that we would welcome some extra help long term to make this placement sustainable....I cannot even get a proper informed answer as to whether I do not have the same rights as I get 'paid' to look after him. It would just be really helpful to know what my rights are....even if it's nothing.
- With face to face meetings with a dedicated adviser
- Yes, yes and duh - yes. What part of "no shit Sherlock" do you folk just not get?!?!?!?!?
- The carer centre could be funded by the local authority to do this.
- Importance of getting the relevant information at the right time

- You can provide as much information as you like and believe me I have cupboards full. Actually doing anything for us is what is needed but more information.
- There is a lot of strategies and paper stating we should get information and entitled to access to services but it is a different picture in reality. I hope this is not another paper exercise.
- As above, worries about how the duty will be interpreted by councils but with this one I think there is a huge role for the 3rd sector to be involved.
- The carers centres are well set up to do this work and their expertise should be recognised and paid for
- It is the Local Authorities duty of care to the carer to make sure that all relevant information is easy for the carer to obtain whether it be online or leaflets in G.P. surgeries, Library, Post Offices. Hospitals. Support Groups. Maintaining and updating information is also important.
- With the developing integration of service providers in the statutory, third and private sectors, it is much easier to access information that will meet the above criteria and more. Co-production of information leaflets will ensure an all-round approach to guidance through the maze of services that will be more detailed and thus more useful to all concerned
- Yes, because legislation changes and carers may not have the time to keep abreast of changes or knowledge of legislation. LA's should provide the information in a reader friendly format which is jargon free.
- Again this should be social work or carer centres.
- A carer who looks after someone for 24/7 should have a support plan to allow the carer to have some time for themselves.( most of us would use this time to have a good sleep)
- We don't hear from our care managers enough as there are too few of them.
- Not enough information available or given to the people who need it. My husband went to our local social work in king street, Wishaw and asked to be assigned a social worker. He was told by the staff on the desk that he must have a GP referral to get a social worker. So he went to the GP and told him what the staff had told him. The GP then give my husband a letter to take back to social work telling them that my husband was in titled to a self-assessment and that he was not happy with the way social work had handled my husband.
- If local authorities are told anything less than a duty then it will simply not be done. If they are given any leeway whatsoever nothing will happen
- When both my children were diagnosed with autism I was given no information. I did not even know what autism was.
- This role is often filled by charities.
- I again reiterate all this is pointless unless the relevant agencies are FORCED to meet the assessed needs. Otherwise it's just pointless
- Importance of getting the relevant information at the right time.

- At the moment all carers in Scottish Borders are foisted off on the Princes Royal Carers Trust (I think it's called). Unfortunately, if you have a personality clash (as I most definitely experienced - I was being TOLD what to do, not offered advice & support) I have nowhere else to turn for day to day support.
- Not only should they establish and maintain an information and advice service but local authorities should be ensuring that carers know about it, by promoting it far and wide, through voluntary sector organisations and community settings where carers and people go eg libraries, health centres, post offices, banks, shops, council offices, police stations, bus stops, local village shops etc.
- This should be available to carers right at the beginning of their caring role whenever that might be
- Important this is not on-line only based information. People need information to be made live and relevant to them and their situation, Moreover, need to be sanctions if this duty is not met otherwise meaningless.
- Perhaps in future we'll be acknowledged and supported properly when it is seen what assets we are.
- Yes they need to take on this role and should have trained staff that know the job and can do the job well.
- Of course there should be this duty of care.
- And to ensure the recommendations are carried through
- Would like more knowledge given about Nursing and Residential Care homes to be discussed far more. Just reading a report on Care home ratings I don't think tells the whole picture. Dom Dentists visiting residents could give more enlightenment on what actually goes on.
- It is essential that better identification processes are developed and information of pathways to assessment are accessible to all Carers.
- If this is not done in most cases nothing will happen.
- Absolutely as 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
- Awareness raising of available services and where to get help and support early on
- Yes, and it should be provided by a local independent carers centre who can provide independent advocacy and advice, not by social workers.

Question	Yes (%)	No (%)
11. Should Carer Information Strategies be scrapped, provided that Health Boards would still continue to provide funding for carer support?	25%	75%

#### Comments

- Here could be slippage in attention to the needs of carers without a clear strategic direction
- Provided that there are minimum standards and no aspects are 'lost'.
- 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.
- Who is to say that the money will be ring fenced and used for carers support???
- Not really sure about this but ticked no because concerned Health Boards may not provide what's necessary.
- Would they still continue?
- How would this be monitored if it is scrapped and would the funding be reduced overall a lot of carers are unaware of Health Board Strategies?
- What would the mechanism be for health boards to have to continue to provide funding for carer support? CIS should evolve into something else perhaps.
- CIS required at least until there is more evidence of how the integration of H &SC is working on the ground
- They should work in partnership with each other the integration of health and social care should aid in this
- 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.
- Removing any onus on Health Boards to be aware of unpaid carers and their need for support is a backwards step. The Carers Register is poorly managed and monitored and this has led to GPs ignoring it. It has no purpose, therefore is redundant. The information the register could provide if well managed is lost to everyone. The benefit of identifying the carer at the first point of contact and the integrated approach of NHS staff alerting L.A. staff is lost. Thereafter, supporting carers is a game of catch-up.
- Health Boards are also strapped for cash
- Not everyone uses health board services on a regular basis. We seldom visit GP and do not have a consultant as autism is not curable, hospital visits are not required. General health good.
- In Fife where I live the carer information strategy and the monies from it only seems to go to cronies, people in the know, and it's an elite club. It's been my experience that carer information strategy workers are ill informed about carer needs or information that's about. Another waste of resource and time.
- Must be very transparent and explicit identification of funds and where they have gone, who is responsible for them and the mechanisms whereby they are accounted for
- Not something that would be important to me.
- Bad idea and I totally disagree

- The local councils and NHS should pull their socks up and start to work together for better care in the community. Only by collating the information and working together will strategies work to the benefit of the person who is sick and the carer.
- Would like Strategies to be more public. e.g. what Strategy is there for deciding who merits Nursing Home Funding? Also what strategy is there for getting a loved one moved out of one Care home into another? How is the waiting list decided? Is it the same for Private and Council run?
- Costly exercise which is not necessary - all funds should be used to provide help /breaks for carers not spent on information. There is too much funding spent on needless paper exercises already.
- Carer information strategies help ensure that money is used for carers. It is essential that carers and carer organisations are included at strategic level.
- Think there still needs to be strategies as there are new carers every day
- Joint strategy perfectly acceptable.

## DUTY TO SUPPORT CARERS

Question	Yes (%)	No (%)
12. Should there be a duty on local authorities to support carers and young carers, according to an eligibility framework?	94%	6%

### Comments

- It is very difficult for people on the outside of a situation to be able to assess the needs and requirements. The important thing is to recognise situations which could put people at risk of reaching crisis point - regardless of their position on any framework. Preventative support is vital.
- If you are a carer, there should be no eligibility criteria. Folk provide different levels of care and often under value the amount of care and support they actually do give
- There should not be any eligibility framework for carers.
- As and when needed there are carers who may need minimum help and others who need maximum help.
- 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.
- And the eligibility framework should be a set of national standards and take prevention into account
- Currently, there is no framework where young carers can be identified within Education. This is an appalling lack of duty on schools and teachers to be aware of issues around which the child/young person's health and wellbeing can be supported. It is urgent that the Scottish Govt, who is leading the



way in supporting the rights of all carers, have not considered including Education in these debates. We have no idea how many carers or young carers are working for us in Scotland.

- What constitutes the eligibility framework?
- Young carers require special help, not fair on a young person to have to be a carer for someone, regardless of how close the relationship to them
- Always, always a duty. As I say if left to "guidance" it will never happen
- And the local authority should be monitored and evaluated according to the performance of their duties. By an independent watchdog. It's been my experience in Fife that local authority social work service are a law unto themselves, can do what they like with public monies, and not be accountable. Complaints processes are meaningless. They say it's a "learning point" then don't learn anything.
- However, eligibility frameworks often become gatekeeping mechanisms - need to be transparent with a focus on care identified support not this is what we have and therefore all you can get (or not)
- Yes they should and it should be 24 hour support
- Eligibility Frameworks can be used to ration support
- A carer is a carer. Why should they need to be eligible?
- However it is important that the eligibility framework is not placed at too high a level meaning many carers would be ineligible for support. 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.
- These questions are worrying. Are we assuming there should be an eligibility framework from the start. Yes to duty to support carers. That duty should be opened to all, as should the support. Not all will need it so any counterarguments about cost must be tackled. Go back to the opening chapter of the carers strategy. Supporting carers is a no brainer economically ...and in terms of demographic trends. We don't support carers there is greater demand on statutory services; more leave the labour market. We must better support carers as we seek more widely to reshape care and integrate health and social care.

Question	Yes (%)	No (%)
13. Should there be a duty on local authorities to provide and promote short breaks?	95%	5%

#### Comments

- 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 daughter to adjust to it if it had been offered earlier - but she now looks forward to her respite breaks after a shaky start.
- Not means tested breaks

- Again I will say No Shit Sherlock!! Why shouldn't they be providing AND promoting these breaks. Often it is carers who share this info, usually having found out about it by sheer luck
- The term "Short Break" can be misleading as some carer's will require other ways of relaxing. Short break suggests time away of longer duration than may be required. Some people may just want a couple of hours now and again to pursue a hobby or interest. Many carers do not have spare cash to fund any spare time.
- Yes yes yes
- Oh good another tick test for us to pass. The person we are caring for has already passed the eligibility criteria to receive care from the LA - whether they take it or not. They have probably undergone a DLA/PIP assessment and now you want to put me in a category? I have been a carer for over 20 years and in all that time nothing has changed.
- Carers do not always want short breaks but those who do should get it. Also priority should be given for carers to go into hospital as I have found with speaking with other carers they have found it difficult to get respite for the person they care for surely this should be looked at.
- 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.
- Again according to national standards.
- Asking L.As to provide and promote short breaks, is pouring money into a sieve - it costs 300% x the respite budget to administer the respite budget - what a waste! Carers centres charge 10% of the respite budget to administer. To get best value for money and to help more carers and the cared-for, pass the budget to local carers centres to administer. They will support more carers, identify hidden carers and provide ongoing support rather than a single intervention.
- Yes, LA's should provide this information up front rather than waiting until people reach breaking point.
- All carers require some respite to enable them to re charge their batteries
- Breaks are essential. Employed people get time off, so should carers who often work during the night as well as daytime.
- This is ESSENTIAL. If the carer falls ill due to stress etc., THEN what is the cost to the local authority?
- Short breaks can re energise carer and beneficial for stress relief.
- Short breaks are pointless if there is nowhere for our carees to go - hence my sons petition to the Scottish Parliament regarding the lack of palliative care respite facilities for the age group 21 - 45. His petition has been referred to the Health and Sport Committee.
- SHOULD BE MEANS TESTED
- Ability of carer to transport the person to a care home should be examined and appropriate support provided ( Ex if my wife has to go into hospital she is transported by ambulance due to her condition but this type of help does not seem to be available to transport to care home when carer needs break)

- Issues around funding remain. I am under the impression that I would have to take a short break at a recommended provider - of which there is only 1 and not in a place I would care to visit. Plus I don't want to be surrounded by other carers, I want time & space to myself. Perhaps issuing a carer with a fund with a maximum amount would be better.
- With the emphasis on promoting, to everyone not just their "chums" or people they deem "suitable". Again in Fife it's been my experience that a chosen few get what's going and the rest of us are excluded. Or those with the loudest voices can claim the rewards while the folk who quietly do their caring are left to get on with it.
- In times of severe stress these short breaks are very necessary but perhaps there should be a limit on the number given to each carer
- Stop the endless waiting for a break, waiting for a person to leave to get their place.
- I did not know this until my local carers centre told me and gave me an information pack
- It would be great if the Carer could just ring up the Care home and get a week or a fortnight booked instead of having to sit in a Travel Agent, be offered dates then sit there and phone the Social or Home to see if the dates are viable
- This should be built in to all carers support plans. It should have breaks available no matter what level of support carers are giving as all carers need life outside caring duties
- Definitely as this is may be their only means for respite
- Scottish Government must make LAs duty bound . LAs are shamefully ignoring carers wellbeing i.e.; mental exhaustion & burn out, it needs addressed urgently.
- At the moment its all about being the first with the breaking news as a trickle of new money comes through. Those with the best information get the most benefits, the people in dire need get almost nothing.

Question	Yes (%)	No (%)
14. What are your views on the introduction of eligibility criteria for support for carers?	Narrative answers... see below	Narrative answers... see below

#### Comments

- Not sure - all carers should be assessed on their individual needs.
- 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.
- At least people would know what they were entitled to

- I agree with this
- If a person is defined as a carer then he or she should be eligible for support. The definition may need to be refined.
- Every carers situation is different and every individual is different. Somebody will miss out if you put rigid guidelines in place
- I need to find out more about the criteria but it's important carers' needs are taken seriously.
- All carers should be supported regardless
- It's a good idea, those in greater need should get the help required.
- They should all be eligible.
- It will be good to have in writing what minimum support LAs must provide
- Totally disagree. It is wrong.
- Depending on how criteria is set. Some of the professionals who support carers know very little about the diseases that the person we care for and the affect it has on them holistically that also goes for the carer. Criteria can be a form of keeping budgets low, staffing and on paper sticking to it without empathy for the carer
- As above, all carers should be able to access support and have a plan drawn up no matter what stage they are at in their caring role. In fact, the earlier they are supported the better their health and wellbeing outcomes are likely to be at the end of their caring role.
- Any eligibility criteria should be transparent and carers should be involved in agreeing them, reviewing their implementation and auditing the accruing evidence of efficacy
- Think its sensible as long as reasonable criteria
- think it's the way forward
- As long as criteria level is not set too high and therefore most carers will be out with scope
- None. Sceptical that anything will change.
- Depends on the criteria - no black and white view
- It is well known that Philadelphian lawyers can find loopholes in any criteria. All L.As have them, unpaid carers don't. Whilst this is good for Philadelphian lawyers, it's rubbish for carers. Once again, Carers Centres see carers regularly and can watch the effect of their caring role. Eligibility is clear if you know carers, trying to define what 'too much' means is a maze through which clarity is lost. For everyone who says white, someone will say black.
- There are some carers who receive more help and funding than others and it should be based on the amount of care and how profound or disabled the person you care for is
- All carers should be eligible.

- Funds are limited and those most in need should receive help as a priority.
- Support requires to be person centred and as such eligibility requires to be considered to ensure appropriate targeting and use of resources
- If a carer needs support they should get it. Simple!!
- Eligibility will leave some carers (especially older or young carers) out of the loop
- I have no problem with this.
- A wider range of services and support for carers and the people they care for.
- Who would decide the eligibility?
- All carers should be eligible to apply for support. An explanation should be given if support refused.
- It infers money budget cuts and means some people who really deserve help won't apply. ALL carers need to be assessed.
- great idea
- Not happy with it
- All carers should be eligible for support albeit varying levels depending on individual circumstances.
- Whilst not desirable , I can understand the necessity for it.
- COULD MEAN PEOPLE LOSE OUT
- About time - heavy end carers should be prioritised as a matter of urgency
- I think it's a good idea.
- This will have to be monitored. I'm always suspicious of eligibility criteria, thinking of Jobcentreplus and work capability assessments, and the havoc that has caused.
- If the eligibility criteria are set too high, it could make it difficult for some carers to access the support and help. A eligibility framework should be co-produced with carers.
- Again not sure about this because needs do change sometimes quite rapidly
- As above - often misused. Moreover, some people don't see themselves as carers so descriptions of the type of things a carer might do for someone needs to be integral to any framework
- It lets authorities gauge the scope and scale of the work carers do.
- It's just another way of cutting back
- Some who is a carer is someone who cares for another person and it is as simple as that and support should be offered with meeting any type criteria or eligibility. The Government for get people save them millions per year so the support should given without meeting any type eligibility or criteria.
- Agree with this

- There should be support for all carers as their caring role can often change and vary in intensity.
- Great step forward
- Eligibility criteria for support for carers gives them recognition of the work they do and hopefully access to help.
- It is just another form of discrimination.
- If the person being cared for is happy with the person that looks after them then that is how it should be
- The Carers should be involved in the setting up of such criteria
- Think Age should be a huge Factor along with Disease, Alzheimer's, dementia, Stroke, Cancers. Anyone with any kind of violence should NOT be placed in an Elderly Care home
- I don't think there should be one. Some carers have a lot of caring to do and cope very well other have little to do but don't cope well with it. Carers are all individual so eligibility shouldn't be decided just by the amount of care they are giving.
- Not sure. It depends on how authorities interpret it.
- I think it is necessary.
- Concerned about how it would be used by local authorities as in SDS they have raised the bar thus excluding so many people who actually need continuing support
- Think it's a good idea as those who are in most need should get most help
- The eligibility criteria needs to support carers regarding their health & wellbeing for carers to continue, living in Glasgow has been very stressful for carers.
- Fair, equitable and transparent eligibility criteria across Scotland are acceptable. This could counteract the current grossly unfair 'postcode lottery' situation.
- More unnecessary paperwork which could be used as stalling tactics
- All carers should be eligible.
- I think I answered this above. Why are we even asking this question? These shouldn't exist.
- They are fraught with bureaucratic minefields, and ultimately doomed. Ask carers what they really need: and they will give you an honest answer. Use In-Control direct payments as the model.

Question	Yes (%)	No (%)
15. Should there be a duty on local authorities publish and promote a Short Breaks Statement?	93%	7%

## Comments

- 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.
- As a means of communication.
- Not sure - seems that they could spend more time writing statements than implementing the breaks. BUT - a level of accountability is needed
- A lot of carers do not know what is available to them.
- Providing they truly support it
- They should also have to provide annual figures on how they are doing with this provision
- Still should be in partnership
- 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
- Local authorities should make it part of the carers assessment forms and be completed on the form. My experience is that short breaks were never mentioned to me when having carers assessment done, I had to ask about it. This shouldn't be the case, short breaks should be mentioned as part of the process
- Not really needed as social workers should know this information and offer it if required
- See my comment above - short breaks are pointless for us when there is nowhere for our severely disabled ventilator dependent son to go since CHAS are introducing a cut off age
- And to continually review what's in it, who they're writing it for, to involve carers and the cared-for, in creating it. Get the experts by experience involved.
- That would be an improvement
- It should be common knowledge given to carers as part of their duty of care.
- More money used not in a practical way.
- Without a statement many people would not be able to access short breaks.

Question	Yes (%)	No (%)
16. Should local authorities be required to ensure there are sufficient services in their local area to meet the needs of carers?	98%	2%

## Comments

- Carers do incredible work for the people they support. As a society, we should want to ensure that everyone has the best possible chance to have a fair quality of life with the support they need being on hand
- To establish a national standard that all authorities recognise
- In my area, North Lanarkshire, there does not appear to be any support services or therapies for people with dementia.
- Yes, but it'll never happen says cynical me. I have been through the \*your son needs services, but we do not have the money to implement the services\*
- It is always useful to know where to go when one needs help and to be confident that there are sufficient resources there to meet the needs.
- Close work with the carers centre would help to identify the services needed
- Unfortunately unless money is ring fenced nothing will change.
- Local authorities have cut their budgets to the bone. They have care managers in place who do not assess the service user properly they do not have the knowledge about physical and mental disorders hence make decisions based on what they see. The carer knows the person that they look after better than anyone else.
- Should be a legal requirement councils always try to cut corners self-serving etc. in party political fighting just look at Argyll and Bute problems
- where possible - often there won't be - it is still nice to be acknowledged as a carer even where there are not resources to provide further support
- If the situation remains the same and current duties remain after this process. However, integration should be encouraged throughout these proposals to give it strength, vigour and impetus. The approach towards L.As should not be punitive but inclusive. All members of the Integrated Approach should be ensuring sufficient services exist - this is a shared responsibility - as it is in every area regarding these Govt proposals.
- most definitely. Yes, there are not enough resources in place to meet carers needs.
- At the moment my local authority neither know nor care what is in their local area to meet anyone's needs
- There are recognised sources to support in Inverclyde particularly offered through more of the 3rd sector. Perhaps the need for more recognised of 3rd sector. Perhaps the need for more recognition of 3rd sector as parties as opposed to creating new Local Authority services.
- They will need more funding.
- absolutely. It makes sound financial sense and will help prevent carers becoming unwell due to caring responsibilities. Someone will have to keep an eye on local authorities to see they do what they're meant to. An independent panel with a range of voices.



- At present this is a postcode lottery
- The 'marketplace' needs to have more within it and this happen through support of the voluntary sector to develop options etc.
- Local authorities, i.e. social workers, don't even know what is in their area never mind ensuring there are sufficient services
- Obviously - times are financially challenging but carers can't sustain a caring role without support and breaks ...inevitably you will end up with two patients to look after!
- I live in Inverclyde and these services are very poor and need improving
- Urgently needed.
- Absolutely. I am sick of hearing 'we don't have the resources' opt out. It would be farcical to allow them this excuse and a waste of this consultation.
- Cannot understand why Care homes are not all on one level with rooms all facing into a central atrium. Also don't think Elderly should be in with Full blown Dementia and related. Different if it strikes once they are in. It's very depressing for chatty Elderly to sit at tables with anyone they can't talk too. I visit my Mum and it's so depressing to find the inside door boarded up because the Dementia and difficult ones are downstairs? Also to see My Mum sitting at tables with others who are in a different World. I don't think it's good for my Mum's sanity either!
- Not just information exercises. Practical support is needed respite breaks.
- Without this carers support plans will become meaningless. This already happens with those being cared for.
- The carer needs to be taken care of first and foremost in order to continue in the caring role
- As long as it's not tea & coffee mornings (classed as a short break by LAs )
- They need to be held accountable
- No point in identifying carers needs if there is not the services available to meet their needs.

## TRANSITIONS/STAGES OF CARING

Question	Yes (%)	No (%)
17. Should the Government issue guidance on managing stages of caring so that Carer Support Plans always take into account the effect that these different stages may have on carers?	95%	5%

## Comments

- 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 care requirements of someone can progressively increase over time, eg. with dementia.
- Yes - some people may need life long caring, they may be terminally ill or have a life limiting condition. So these people will need different stages - especially at the beginning and near death stages. Some people care for a family member/friend with cancer. (just taking this as an example)... Often, these people will go into remission and the need for caring may have come to an end.
- The caring role can be very tiring, as the situations change so the carer gets more worn with the tasks required, so will need more support.
- More and different help may be needed at different
- Hopefully not another paper exercise by the government. They have to be committed that the information given will be used to support the carer and the service user. Will all professionals involved with the carer use it.
- Transition stages are extremely important, as are ageing carers, and carers who care for many decades. They should also take account of the educational and employment requirements of carers and the effects of caring on costs, income, pensions etc.
- Although there is not a one size fits all with this, and often this penalises specific conditions (such as Asperger's that are different from the norm in many of their requirements. i.e. this should be condition specific in many respects
- Transitions means changes and by recognising that carers and the cared-for, will, by the nature of life face a number of transitions during their life-time. Getting older regardless of starting age of being a carer or a cared-for is an obvious transition. Degeneration and deterioration face the majority of those living with long-term or terminal conditions. People who are diagnosed as having multiple needs, whether young children, young people, young adults, adults will also have the 'growing up' process to get through and each stage of this is full of times of decisions. These decisions need to be informed and supported to ensure the best route forward is taken and vulnerable people kept safe and protected.
- Assessments of carer/person being cared for should be carried out e.g. annual with the option of when there are changes the assessment is brought forward.
- Carers move through different stages of caring, especially if cared for suffers from dementia
- Especially if there is a hospital stay/release.
- Necessary due to certain progressive type illnesses and length of time caring i.e. short term caring for terminal conditions and long term caring for progressive neurological conditions.
- As Alzheimer's progresses then care needs increase as does carer support

- The Government should take the lead on this and keep an eye on local authorities. Especially in Fife which is a postcode lottery for carer support in mental health.
- As I have said previously particularly in mental health the stages and stresses can vary enormously
- However, guidance is something that can be ignored. Needs teeth and clear statement of course of action should the guidance not be referred to etc.
- Definitely when cared for person transitions from child to adult services, what a horrible & stressful & lonely experience
- They should leave that to people who deal with this every day like the carers centres .
- Urgent need ... Having gone through post 19 transition and all it entails more emphasis needed on Carers needs as well cared for person needs.
- This question sounds as if it is coming from a Nanny State. It misses the point that carers are very valuable to the government and guidance from them (government), once put down in writing becomes something that depending on the reader/body who will judge the carer by the publication according to their own personal adaptation of the stages of recovery.
- Very much so as this would not support carers any other way in a lot of cases.
- The important thing is that Carers should be involved in planning, implementation and management of such
- This is urgent as many families have no support when their young people are 'children'. This means little support offered as they grow older and can often mean that when support is given it has to be at a much higher level than it would have been if regular help had been given.
- Surely this should be part of a good assessment.
- "the whole world is a stage", and caring no less a part of it. These plans create jobs for the boys and girls, and get binned. A carers life changes from day to day, hour to hour. We don't actually need these plans at all, the back of a fag packet is fine: we do need local, flexible action, personal autonomy, and fast access to professional accredited resources like residential respite in an emergency.

Question	Yes (%)	No (%)
18. Should young carers who are likely to become adult carers have a Carer Support Plan agreed before they reach 18, so that support can be put in place as soon as they become an adult carer?	98%	2%

#### Comments

- This is a situation which is known about in advance and should be easy to plan towards to ensure smooth transition to adult services

- Well, from my experience, my son who is now 21 has fallen off the radar when it comes to the carers unit. He is still caring for his brother and the carers unit just didn't do anything to help him. So yes, a plan would be good
- But it rarely works.
- 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 is required for the service user in advance of any decision made.
- 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 eg staying on at school, going away to university, taking employment away from home etc
- as long as they still have the choice and human rights
- continuity is important
- It is not unusual for young carers to have their future choices limited by their caring role. It is an abuse of their rights for any young carer to not have the same choices as their peers. There is also the horrible place of being in the 18 - 25 age bracket, where young people seem to become invisible and are not acknowledged and supported whether they are caring or being cared-for.
- If not done they may lose out
- 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
- But they must be supported as young carers. Young carers should NOT really be taking on such a challenging and difficult role. They are the child NOT a carer. It is a huge burden for them.
- Maybe there could be a Support Plan for Young Carers as well...this will make transition to Adult Carer much smoother
- Vulnerable age group who may require additional support.
- They shouldn't be young carers in the first place - its child abuse.
- well before they are 18
- should not be young carers - but as fact of life yes absolutely and that once an adult the 'right not to care' is promoted and so plan is about what will be put in place to support the cared for person so that the young person's desire to go to college for example is something that is seriously and meaningfully addressed.
- They are still carers and it their entitlement
- Continuous support should not be compromised.
- Far too much reliance on young carers who have few rights.
- They should have a choice in this and a right to a life outside caring

- Yes, though as stated above, I'm not a big "Plan Fan" - I like the kind of plans that involve regular discussion and dialogue, not the plans that are like the Ten Commandments: "Thou shalt honour thy father and Mother for six days and on the Seventh Day shalt thou receive two hours home care, it shall be no more than two Hours, and no less than Two Hours .. not Three, nor One, but Two shalt be the number". Hmmm!

## CARER INVOLVEMENT

Question	Yes (%)	No (%)
19. Should local authorities have to produce a local carers strategy? Should young carers be included in this? (tick all that apply)	Yes, a Strategy for carers (53%) Yes, a strategy for carers that includes young carers (93%)	2%

### Comments

- Only by learning about and considering the needs and experiences of all carers can a fair strategy be produced
- Of course they should - You need to know what is going on in certain areas, know what support is available. Caring in a city environment like Glasgow is sooooo much different to caring in a remote rural environment like Portree on Skye
- Younger Carers have different needs and rights, a proper education, the right to have a childhood
- As long as the actions/aims set out in the strategy reflect and have real practical developments that assist carers in their role and not just parked on a shelf.
- More plans. Plans of plans. More paper work. More talking. More committees.
- Local Carers strategy is produced but not adhered to. Will there be any legislation so that a carer can take them to task if they do not meet these.
- Involving carers and young carers in the production of a local carers strategy will only work if 1 the carers and young carers know their voice will make a difference 2 the process is conducted in English 3 the carers and young carers have been prepared to take part prior to the production of LCS 4 the need for limitations is explained throughout the process - lack of resources etc. etc.
- Just playing with bits of paper again and not solving the problems faced by acruar carers on the ground
- As long as the actions/aims set out in the strategy reflect and have real practice in developments than assist carers in their role
- Local Authority/Government need to recognise carers do not have time/energy to read and comment. There is the need for more user friendly shorter material to gather carers news for those who want to have a say but don't have time to unpack info.

- Again, involving carers, young and old, in its creation. But a wide range of carers, not just their "chums", folk who tell them what they want to hear. Critical voices, people who haven't been happy with the support provided. This is what will bring about real improvements and effective management of resources.
- Anything that affects the carers or young carers should be talk over with carers as they know better than anyone what is needed.
- I don't think a Carer who has problems looking after drink and drug problems is in the same bracket as looking after Elderly. Totally differing needs
- All carers no matter what age should be involved in local carer strategies.
- Yes, but do keep it short and sweet or no-one will read it, specify hard cash, hard respite-week targets, number of carers to have power over their own budgets, carers helped into employment and through college: not the usual touchy-feely waffle about involving people and all that guff.

## CARER IDENTIFICATION

Question	Yes (%)	No (%)
20. Should the Government introduce a duty on GP practices and local authorities to develop and maintain a carers register to support the identification of carers?	Yes – GPs (17%) Yes – LAs (5%) Yes – both (75%)	2%

### Comments

- 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.
- I know my GP does as much as they can to make sure they have a list of those who are carers. But i'm not sure how good it is - often if you care for someone, they don't actually stay with you, so it's up the the carer to let the GP know. And sometimes, people don't always consider themselves carers - they just fell that they are helping out, without actually stopping to think how much support they do give
- A system ought to be in place whereby if a patient who has a carer has a need to seek any kind of medical help the health official is made aware that the patient has a carer. This way the carer can be kept informed as to what is happening as often they know the patient best.

- These registers could be used with permission to ensure carers and sent up to date information on services and support available to them
- All voluntary and statutory organisations should be responsible to identify carers. An example an application for housing could identify carers.
- I have lived in 2 different local authorities. One GPs surgery did not flag up carers, the second does but makes no difference.
- The register should not just be used for data collection. I would like it to identify that perhaps the carer has not been at the surgery for some time do they need a check up? Trying to fit in surgery appointments for carers can be difficult can there be some way of GP's being more flexible or carers being allowed to speak to a GP and if possible with the doctor that has been treating them for continuity of care.
- But they need to connect those registers with the providers who can help and support carers and families. No point in just number counting if it doesn't result in change for the carer.
- 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.
- Many people don't realise they are carers even after giving up part of their work and arranging their lives around another person - often it is a gradual progression - like billing a frog....#
- The current Carers Register has foundered because it lacks purpose - why simply make a list? It is clear, that the first point of contact will be the GP. 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 carers' health or wellbeing shows itself. Carers will listen to GPs and if they recommend going to the local Carers Centre, they'll go.
- my understanding is that this was already in progress

It was our GP that provided information about careers and put us in touch with careers together. No one else same to give a monkeys about providing information on any help that was available to us. I also look after my daughter who has been disabled from birth she is now just turning 16 and some times we worry about the the help she may need in the years ahead. It's very hard for my husband as he was a foreman in his last job to be coming some that relays on other people to help him and as he said it's very disheartening for him to be getting asked questions by someone who dose not know him or the pride he took in doing his job.

- 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 important to ensure carers own health does not suffer due to caring role and to quickly identify conditions such as stress and depression.
- Why its pointless when they don't provide services

- However there is no point in having a list of carers if there are no benefits to being identical e.g advanced bookings, appointments, health checks annually etc
- My GP practice already does this and it is very helpful.
- My health centre in Cupar has this but I don't know of any benefits from being identified.
- Absolutely, in my experience there is a shameful lack of 'joined up thinking' between the GP, social care agencies and the hospital/health trust.
- My GP practice does this already and it a great idea and should be done as standard.
- If this were to be enacted it should be a unified system.
- Some gps are already doing this and have proved successful
- I would have liked my Doctor to tell me about Nursing Homes
- Important that the existence of the Carers Register should be well advertised.
- GP's 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.
- Wasn't funding already accessed for establishing a Carer Register re: resources and GP practices?
- Absolutely as gps are on the whole rubbish at identifying Carers and don't seem to care
- If this is not done it will be all to easy for carers to not be identified and for support not to be made available.
- Registers don't work and cost far too much money to maintain that should be spent on direct support for carers instead. An opt-in email list would be fine, together with a carers information board in every Health Centre and LA one-stop shop.

Question	Yes (%)	No (%)
21. Should the Government place a duty on health boards to monitor compliance with the requirement to hold a GP register?	94%	6%

### Comments

- This would raise awareness of the numbers of people giving and receiving care - even if the carer did not take up offers of support
- I believe if this is not done the system will fail.



- Only if cost effective we do not need another layer of management. Is there any way the it could be incorporated in the GPS Quality Services.
- Or it will not happen!
- Clearly updating a carer register is very patchy currently and GPS should not be paid just on registering a few but on how many individuals they register, with the proviso that the carer agrees to registration. All patients should be asked regularly if they consider themselves to be a carer
- No point having a register is not closely monitored
- Recognition is sadly underplayed
- 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.
- not all GP practices are up to speed
- 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.
- Yes it should be ensured that this is done as some GP may not do it.
- May be difficult but very necessary.
- For the sake of the carers well being on mental & physical health & it should be fast tracked .
- NO! We don't need more office jobs for the boys and girls behind desks to tick boxes on process issues : we do need to direct scarce resources towards delivering and improving outcomes that have a real impact on the quality of carers lives.

Question	Yes (%)	No (%)
22. Should the Government ensure that good practice on the use of the carers registers is promoted amongst health boards?	97%	3%

- Communication is important
- Again I believe this to be in the best interest of all concerned.
- Simply having a register of carers is not enough.
- There should be a duty off all health boards, LAs and Voluntary sector to hold and share carers register.
- Yes, there has to be thought about how it is used.
- Yes but they also should be required to make use of this information to alert carers centres and instigate carer support plans

- Whilst this can be helpful, it often backfires and you end up with disgruntled practitioners. 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. Carers centres can provide a simple leaflet for those who are new carers to outline their services and ensure the carer knows that they are there when they need them,
- Again, health professionals already overstretched in the Community
- Could cost money
- I have been dismissed as irrelevant several times when Mum's had an admission into hospital. In the end I have had to resort to waving Power of Attorney around to make sure I am listened to. That is extra stress which can be so easily avoided.
- I am happy with government keeping an eye on health board practice re carers register, in order to ensure good practice.
- GP's should report to their health boards on a regular basis.
- However, there is an over reliance on 'sharing good practice' without ensuring that it is incorporated within each local authority
- Annual reports might help and follow up on support plans and implementation.
- Not only promoted but it should be enforced.
- Total waste of time, tick box exercise.

## HOSPITAL DISCHARGE

Question	Yes (%)	No (%)
23. Should the Scottish Government introduce a duty on health boards to involve carers in hospital discharge planning?	100%	0%

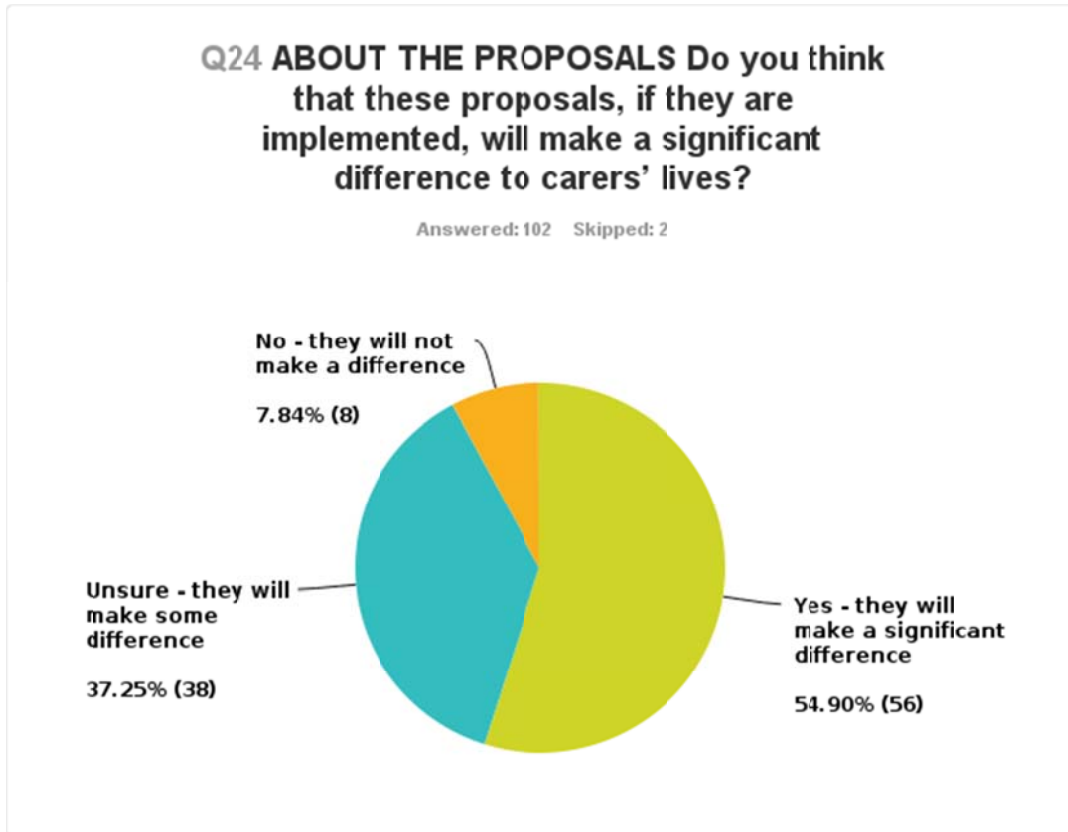
### Comments

- This is vital to ensure that unprepared discharge does not result in a crisis situation
- Yes - some patients are discharged home and there is no one at home to help look after them. If they have been in hospital for a while, they may not even have basics like bread and milk.
- Often the carer has the best knowledge of how the patient will cope/be cared for at home.

- Most often the carer is seen as part of the package of care at discharge. The carer should always be informed and involved at discharge planning.
- Carers need to plan for taking the person they care for home some hospitals give little warning. There maybe the need for OT'S, Physios, community nursing staff etc to be involved and overall the carer is centre for the success in keeping the person they care for being readmitted.
- Such a crucial time and carers often report feeling unprepared for the increased needs the cared for person may have on return home. Continuity from Hospital teams should cross over for a few weeks on the persons discharge, so that dialogues with community teams is more effective and people are less likely to fall through a missed communication gap between hospital and home.
- There would need to be some clause/honest discussion where the cared for did not want this, and why, and what level of responsibility a carer would be prepared to take in such circumstances
- This should be working in the Hospitals already
- Discharge from hospital is a fraught time for carers and they need to be involved
- And other arrangements with the cared for person - especially in the case of mental health where in my experience they are often actively excluded "for reasons of confidentiality" until much too late in the proceedings
- Apart from being good practice, it also means that NHS staff are sure that patients are being sent home to a safe and appropriate environment, with those who will take care of their patient, ready and prepared for the role of carer. Would prevent re-admissions, falls, harmful situations and crises.
- Through personal experience recently my mum was discharged from hospital medical ward because she had onset dementia. I had my concerns about patient going home to live alone and 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.
- This is essential, as the carer often knows more about the person being discharged, than the hospital staff
- Most definitely.
- OMG, this is ESSENTIAL! Discharge is often the point where the system breaks down into the community. The carer is left unsupported.
- If carer who also works then consideration should be given by hospital on ability for caring duties where patient may be clinically well but more short term physical care may be required.
- Patient often being told negative results of tests/diagnosis without carer present causing great distress to patient particularly for those living with a mental condition.
- Approx 1.5 years ago a patient with dementia was left in a room without supervision resulting in them walking out of the hospital in distress of their carer/family member who received a call from the patient alerting them to this fact. The carer did not receive any phone call from the staff at the hospital alerting them of the patient's disappearance.

- It is already in place at my local hospital - but sometimes one has to wave a PoA around to get involved instead of being confronted by a well meaning nurse who informs you that your mother's being transferred 20+ miles away & that I should be happy about it. No discussion, nothing.
- Psychiatric hospital discharge is particularly an area of challenge for carers as we are often left to pick up the pieces if traumatic treatment has ensued. The first few days and weeks after discharge are very stressful for patients and carers alike.
- There should be a duty on Health Boards to inform carers in hospital discharge planning
- I think this is vital in the recovery of the person cared for and for the wellbeing of the carers
- Obviously they should ! If the hospital deems a patient fit to return home but the right level of support is not in place then a rapid re-admittance is likely costing more money and perhaps more importantly more trauma and distress to both patient and carer.
- This is done by Inverclyde Carers and it very successful and well used so well worth doing.
- There is too much of rushing them out of beds or Elderly bed blocking cos there aren't enough Nursing Home availability. I would also like to bring back Matrons in charge of each ward
- Carers must be involved as at present too many people are discharged without the correct level of support and end up back in hospital very quickly.
- Is it not already in NHS guidelines?
- This is just good sense. Too often people are sent home without discussing care needs or the impact on wider family...or indeed without appropriate support in place. I suspect lack of proper discharge planning lies behind many readmissions to hospital.
- Well, yes and no. I would phrase it thus: "The Scottish Government should introduce a law that Carers, and Carers alone, have an absolute and unquestioned veto on the date of discharge. Carers do not have a legal duty of care, but Health Boards do". So we carers have every right to decide when WE are ready to return to care. Unpaid, and out of the love in our sweet little caring hearts. I don't trust Health Boards, and neither does anyone I know, to behave with integrity: they will basically do whatever their hard-boiled accountants tell them they can get away with. You know this fine well, and so does everyone else. So why pretend otherwise?

## SUPPLEMENTARY QUESTIONS



- 104 responses
- 100% of respondents happy for this to inform our response.
- 96% of respondents are adult carers, 4% former carers. No responses from young carers.
- 25% are organisation representatives (as well as being a carer), 75% carer but not organisation representative.