

'Equal, Expert and Valued'

29th March 2017

Report of Discussion Groups



Short Breaks

What should guidance or regulations say about the form a break from caring should take? For example, would it be useful to illustrate what is meant by a break from caring in guidance (ie, an agreed definition)?

- Need to be clear on how short breaks and SDS should work together
- Needs to be seen in context of carers wider needs
- Duration of short breaks
- Case studies to educate people about all the different options and how to access these for carers and families getting a meaningful break from caring responsibilities by whatever means
- Increased choice and flexibility
- Guidance on when a carer can have a break (regularity exclusion periods – eg I had a break 3 years ago so that's me)
- Needs to take needs of carers and cared for into account, have to consider these separately not 'under the same umbrella'
- Issues with budgets – making sure there is clarity on what cost comes from whose budget eg if break comes via carers assessment, the cared for shouldn't have to contribute
- It's different for everybody – not dictated, led by the voice of the carers eg having the option to go away with the cared for person if that's what's wanted and needed – to get a break from the normal routine
- Clarity is needed on the question of replacement care – whose budget, whose outcomes
- Must be consistency on definition of 'breaks from caring' and applied consistently across Scotland
- These issues need to be spelled out – on waving charges for carers
- Frontline staff must be supported to understand the regulations/guidance on what a short break is to ensure consistent application of regs/guidance

The Act places a duty on local authorities to have regard to the desirability of breaks from caring being provided on a planned basis. What should the guidance say about this?

- Need for frequent/relevant reviews of carers plan – recognising that things change – Flexibility is key
- Replacement care has to be cost free
- Where possible, planning the break has to include the cared for person – the plan needs to take carers and cared for person's needs into account
- Need to recognise that the planning legwork associated with breaks can be off putting for carers – it's not just about financial support for breaks
- More money is needed to enable carers centres to support carers to plan and take short breaks – eg like Dundee CC brokerage model. These funds need to be distributed fairly across the country to ensure consistent support
- General feeling that it would be better if carers centres provided funding and support for short breaks (rather than social work or NHS)

What should be included in the short breaks statement?

- Importance of getting a carers plan first
- Info that enables carers to decide when and how to take a break, what to do and where
- Case studies/examples of the wide range of options
- Communicate carers rights options with regard to SB (eg that replacement care is separate to SB provision for carers)
- Information on support available to plan and take a break (over and above funding for Short Breaks)
- Accessible info – written, online, people – for many people a conversation is far more appropriate/helpful
- Has to define what a short break is (should specify) What matters is that it feels like a break (it's about the outcome not the activity)
- Timescale from request to reply
- A brochure of different places you can go
- Criteria for accessing SBs
- What support is available to help arrange SBs – who to contact
- An appeal or complaints system – who to turn to if you're not happy/if things go wrong
- NO JARGON
 - Straightforward and transparent
 - Easy to understand

Who should the short breaks services statement be aimed at (carers only, or for practitioners and others also)

EVERYBODY: So it must be in language people understand and it must be accessible

Carers, Cared-For, Social Workers, Councils, GPs and Hospitals, Government, Other Professionals, Advocates, Allied Health Professionals, local library, tourism industry, charities, schools, colleges, universities

What should guidance say about building and maintaining a proportionate, but diverse, choice of short breaks provision – both locally and nationally?

- Key challenge – nowhere suitable to spend my son’s budget to get a break
- Using case studies to illustrate the range of possibilities – to stimulate development of new services/options
- Additionality is key – money for SB under Carers Act has to be in addition to existing provision (eg discretionary Social Care funding for respite provision) and used to develop and deliver new/additional short breaks services
- Guidance should say – identify existing spend and respite (historically) then make sure that new funds aren’t absorbed into this.
- Linking into hospitality sector (eg respitality)
- Having examples/case studies that demonstrate the range of different activities that can provide a short break
- Comes back to principles of SDS – choice, control, flexibility, outcomes

What are the 3 key points from this discussion?

Group One

1. CASE STUDIES – Examples demonstrating the wide range of SB options are essential
2. CLARITY – is needed on provision for carers vs provision for cared for (eg replacement care)
3. SHORT BREAKS – a holistic approach is required, taking into account all needs and support

Group Two

1. SUPPORT to plan and take breaks from caring is crucial and probably better provided by carers centres than social work. Without support it can be impossible to take a break.
2. Short breaks must be PERSONALISED – it has to be the right break for the carer and the cared for person at the right time
3. Information about Short Breaks must be ACCESSIBLE to everyone and no jargon!!!

Eligibility Criteria

General points from workshops:

- Do we have to call it “eligibility criteria” confusing and unhelpful
- The NCO tool should be used in all areas – it is risk based and all agreed this was a good approach; it has been tried and tested in Dundee and found working well!

- Risk based approach in all cases best
- Prevention focus must be contained – reducing risk, preventing deterioration of caring relationship

Agreed the wide range of impacts on different areas of carer's life. Impact depends on ...

- Condition of person cared for
- family relationships
- carers' health / age
- carer's finances
- individual personal circumstances
- physically
- emotionally
- financially
- education/training

Agreed they should all find consideration: carer is case manager

What should the process be for determining a carer's eligibility for support?

- It should not be done just by health & social care staff - danger of decisions being resource led (money and services the Council/HNS can offer)
- It should not be done just by voluntary sector – danger of expectations which can't be met; money and responsibility always held by statutory sector
- Joint panels / resource allocation teams, with strong carer centre input – joint working / joint budgeting should apply here as much as in all other areas!!

Who should decide need?

The carer

Who should decide support to meet need?

- Joint and transparent process with stat/vol partners
- Positive example: this has been done in some way in West Dunbartonshire
- Negative example: never done in Glasgow
- Conflict of sole decision by LA: danger it is resource led
- There needs to be provision for advocacy / appeal

What should be in the guidance on eligibility?

- Determining eligibility criteria, and later determining the eligibility of carers for support, should be joint and transparent processes, involving H&SC and Carer Centres
- Should engage the carer
- Should be based on the reality of caring impact and caring risks, not a paper exercise

- Prevention focus!
- Personalised – not one size fits all!
- Focus on early intervention and ‘re-ablement approach’ (investing a lot of resources over short time to re-establish healthy caring relationship, rather than minimal support to just hold fractious relationships together)
- Must include advocacy and appeals!!
- “LA’s are expected to use the NCO tool as foundation and not compromise on the outcome focus”
- also support person receiving care, and carers, to have their rights upheld

Carers Engagement and Hospital Discharge

What steps should Health Boards take to identify that a person is the carer for a patient in hospital?

- Carers should be seen differently to next of kin
- Education for staff to have proper conversations with and identify carers
- Triangle of Care – Identification in admission paperwork, particularly on planned admission. Needs to be core part of acute admission
- Nurses culture needs to be addressed
- Communication – need to talk to carers all the way along, sharing information
- Link to GP register. Ask questions on admission? – included in admission questionnaire. What does carer do when they go in for treatment?
- Link to advance statements and emergency plans
- Need to look at fluctuating conditions such as mental health
- Ask if you have support in place, if no, action to ensure they are in place
- Lead person who is responsible for the care of the person you are looking after – sharing info with consent of carer
- Plan and comms – particularly in Mental Health where person’s care/treatment involves passes eg weekend out of hospital. Need to start at the beginning
- No evening discharges –
- Recognition of Power of Attorney
- There must always be prior consultation with carer before a discharge
- Balance between clinical need and social care needs.
- Case studies – part of training too, this happened, why it went wrong, what could have avoided this
- Getting psychiatrists into a room – they need to hear
- Information for carers on treatment/care including issues like changing stomas – training
- Carer identification is a critical element – ask/talk to people about caring (you are a carer – you’re taking up a caring role)

What practical steps could Health Boards take to involve carers in the hospital discharge of the person they care for?

- Communication – they don't listen or welcome you saying you are a carer.
Denial of services
- Services must be in place
- Staff training so they have the level of understanding of what needs to be in place for carers and the person they care for
- Medically fit is not the same as social circumstances the person will face on discharge (home visit/OT assessment before people come home)
- Carers must be involved in design process of discharge planning
- Staff training and culture change
- Holistic approach – joint assessment of Health and Social needs before discharge
- Support on the ground to keep people at home, they do not necessarily need admitted, support in community could prevent
- More investment in voluntary sector, tackle loneliness, connect people with community, lunch clubs/day centres
- It should not only be those who shout loudest that get help/solutions
- Multi-disciplinary discharge planning, keeping carer informed of situation as admission/stay when it gets nearer, discharge plan should be developed with carer, discharge plan should not take effect until carer's agreement
- Carers need to know about their rights, staff need to understand and act on the logistics and challenges in managing and arranging care, centralising hospitals presents a real challenge for carers (alongside cuts to beds)

How should carers be involved in local developments in relation to the Carers Act, including the 3 areas mentioned above? What is happening at the moment in your local area?

- Pilots in Island area are necessary
- Hospital appointments from Islands – fly time not ferry eg planning doesn't take account of carers
- Telecare apps are useful, but need but broadband
- Wider planning – carers need to be involved throughout
- Communication, logistics, transport, work eg hospital appointments – Carers need to plan
- In North Ayrshire carers are designing and developing carers support plan – a positive example of how carers should be involved
- Involved at all levels, communications at all levels

What are the 3 key points from this discussion?

Group One

1. Talk/communication
2. Understand
3. Act

Understand the logistics and challenges carers face on organising and planning for appointments, hospital admission and discharge

Group Two

1. Communication is critical – involvement from the start
2. Education and Training – understanding carers circumstances
3. Processes for discharge needs to be developed with carers
 - Carer support
 - Community health
 - Voluntary sector
 - Social care
 - Advocacy
 - Mental health support services
 - Community preventative support
 - Professionals, carers, patient, person
 - Good practice – find out what works

Conditions for Successful Implementation

What do you think are the conditions for successful implementation?

- Baseline assessment/review in what carers centres are providing across country
- Carers Centres being key partners
- Utilising existing networks/forums
- More thorough policing/networking of Health and Social Care Partnership to ensure it's working for carers not benefiting partnerships
- Too much focus on recording of information impacting capacity targets
- Pre-existing funding and how that will help to implement the Act
- Money coming in is not new – short breaks jeopardy duty v right
- Carer Positive helps build up understanding
- Education, care, early identification
- Communication

What needs to happen for the Carers Act to work well and make a difference for carers?

- People need to know about it and understand it – carers

- Cut through the bureaucracy and work well for individuals rather than HSCPS
- Link policies more
- More publicity for carers and about carers 'A day without carers'

How can we ensure carers know about the Act and that it makes a difference to their lives?

- Communication with carers, empowerment, carers having accountability
- Through carers centres
- Managing expectation over 5 years

What needs to be put in place for the workforce to be prepared for the Carers Act and to contribute to its successful implementation?

- Guidance
- Education

What role should the third sector be playing in relation to successful implementation and what resources do they require for this?

- Should have sustainable resources
- National orgs can shine a spotlight on local failings
- Sharing good practice

What are the 3 key points from this discussion?

- Having guidance for carers
- More carers involvement in consultations
- Communications
- What can we capitalise on that pre- exists
- Inequalities (gender)

Hopes and Concerns for the Carers Act

How hopeful are you that the Carers Act will improve things for carers?

Not hopeful 1	2	3	4	Very Hopeful 5
1	10	8	7	2

What do you hope the Carers Act will deliver for carers?

- That they will be able to find help and advice easily and people will be there to give them advice in all areas
- General support for all carers as identified as being needed by the carer
- To improve recognition of the needs of carers
- Better system and fairer system – not very hopeful
- Streamlined appropriate support for carers at the right place/time
- Better guidelines – not very hopeful
- Improved services for carers – less red tape, more transparency
- It will deliver human rights for carers
- More flexibility and respect from social workers, council that caring is very stressful
- Regular short break facility for carers who are eligible. Consistency in delivery services to all areas with knowledge on which services are available to them and where. Help with form filling and an understanding of what rights carers have
- More understanding and respect of what carers do and the costs in all senses of that
 - Equality and support and improvement for the future (all carers)
 - Greater recognition of what carers do, that the role carers have is valued, that carers are seen as 'expert' in the needs of cared for and themselves
 - I hope carers will feel more empowered and have a voice in decisions affecting them
- Stress relief, way back to employment, less isolation and increase in self worth
- Recognition for great job they do. An entitlement to better services. Respect from professionals within those services. Continued and appropriate support that meets their needs. Also identify new carers. Help all carers receive services in whatever area they live in. No Post Code Lottery.
- Carers will be listened to. Increased opportunities and choice particularly in respect of respite. An opportunity to have their voices heard when it comes to developing and delivering services
- I hope the Carers Act delivers the relatively small number of rights it affords within the context of what seems like continual 'reviews' and funding cuts
- Consistency, clear guidelines. Should be adequately funded
- Justice, equality, a life
- That the carer gets treated as a person and has rights
- Parity/equality across the country
- Supporting carers as individuals – not one size fits all
- Some more help before people reach crisis point or mentally unstable themselves

- More recognition of the importance of the care role they provide and their needs be supported in that. More actual support (financial and practical) to assist them in their care role
- Will be delivered appropriately. Unpaid carers will get recognition for the work they do. Provide appropriate information for carers on their rights if unaware of them
- An awareness of carers rights and the law to be implemented and not ignored. I hope that this raises awareness of what carers do across Scotland/the UK. SDS eligibility is very in relation to carers accessing support
- Recognition of what carers do for society, rewarded financially for sacrifice given by carers ie giving up work and a normal life, being treated with respect and given the dignity they deserve and not struggle sometimes on the poverty line

Do you have any concerns about the Carers Act?

- Local eligibility should be National
- Local Authority being in control of budget unlike ILF which is not controlled
- Unlike the Care Act in England and Wales, I hope this does result in a positive difference. I am concerned Local Authorities make up the law as they go along, this is why it's crucial that carers know what their rights are
- Not enough funding to provide appropriate resources and services for the carers
- Act will not be delivered in effective ways for all carers to be aware of the Act
- Will there be funding to provide the support needed?
- Will the eligibility criteria be so strict that people don't get the support they need when they need it as they are below the line?
- Will Social Work follow the real spirit of the Act?
- Will things vary from Local Authority so that not all carers are treated fairly?
- Do not feel it is coming out quick enough
- That it will get lost among all the other legislation
- That it does not change anything and there is no improvement
- Under funded
- Uncaptured carers
- Should have taken more advice from carers, welfare rights workers at beginning of process
- The financial package (being not ring-fenced) being swallowed up by the IJBs existing commitments
- Eligibility criteria set too high. Building expectations of carers which may be impossible to deliver (through lack of funding available and cuts to existing services)

- Only that it will not reach all carers. Also that services will only use it as a token
- Money to implement successfully. How to bridge gap between policy and practice
- Dependent on Local Authority priorities and if/how well they engage and listen to carers
- That implementation is not equal across Scotland. That 3rd sector organisations are not recognised as true partners across Health and Social Care Partnerships
- Feel as if it will go off track and not be fully recognised or practised as it should be
- Lack of National eligibility criteria. That budgets matter more than people. SWs can't keep up with SDS assessments – delays
- Issues with procurements, processes and services, rural/city issues
- Just worried that it is a GP service and a pen pushing exercise and will not improve carers rights
- Human Rights are not enforceable
- Adequate resources to deliver the services required is a concern
- Do not think Council etc will fully implement and people fall through cracks
- Bureaucracy – more systems/processes. Budgetary difficulties. Roles/responsibilities (who completes carers plans/who is responsible ultimately for eligibility)
- Won't be worth the paper it is written on or will not be completed
- No additional resources available to deliver services – how are we going to support the identified needs? If more carers engage how will this affect service delivery, quality or long waiting lists
- Yes that it should be nationwide – it won't be

What do you think needs to happen for it to be successfully implemented in your area?

- Better communication with Health and Social Care Partners
- Expertise of local carers centres/support services need to be recognised. Need to be trusted
- It should be equal for all parts of the country, money divided in a fair manner
- The need for core funding for existing service providers – the capacity to deliver the services should not be project. Don't throw the baby out with the bath water/funded
- Education, monitoring and making sure people are fully aware
- Decision makers need to take on board the differences carers make. Also need to think of learner ways of working to counter bureaucracy
- Monitor and Government ensure that there is an overheard
- Adequate resources – clear pathways, information and services

- We need honest, trustworthy councillors, social workers, doctors, officers in West Dunbartonshire but there is a great shortage of these people in the area
- Councils to be more open and not use cutbacks to reduce services
- Whole systems change and hopefully some of the carers policy unit will listen and do their best to influence others. Scottish Government in a human rights context for everyone in Scotland
- More management and meeting for all and to learn what's going wrong and be respected, acted on to gain improvement
- True consultation and partnership working with HSCP and carers and their representatives. Work force supporting carers fully improved of what the Act means for carers
- Voluntary Sector funding to be longer for than annual review in order to maintain staff
- It has to be advertised – possibly through the media
- To be near the top of the agenda within Health and Social Care partners and IJBs. Working group formed to look at fundamental elements of the Act such as eligibility criteria
- There requires a genuine commitment to the Act and carers support provision within the partnerships
- Clear pathways and consistent over whole of Scotland
- Sustainable funding for carers centre
- Training for front line staff eg EPIC
- There needs to be funding and people wanting to do it
- Lots of encouragement/nagging/scrutiny from 'on high'
- Listening to people and to make carers and patient (clients) know more information
- Good links with carers centres
- Adequate money in social work budget to provide the funds for individual carers who are eligible
- To include carers in the implementation
- Much better joined up working between the Local Authority and the carers centre. We need better equity of provision and a change in the organisational culture so that we can focus on carers support rather than saving money
- Strong guidelines for local authority from Government