

Summary of responses to consultation for Carers Review

Carers' responses

Question	Responses	Number
When did you first start thinking you were a carer and what made you aware?	After cared for had a spell in hospital	2
	Cared for unable to do key tasks themselves & manage their own affairs	6
	Gradually crept up - had to give more attention and do more for the cared for person	4
	Volunteer at Alzheimer's Society asked carer if they had contacted Social Services	1
	Upon diagnosis of a condition	3
	At a point of crisis	1
	Care assessment needed for cared for person	1
	Onset of memory problems	2
	On attendance at the 'Caring & Coping course'	2
	Needed help and personal care	1
	Friends saw me as a carer	1
	<u>Other comments</u>	
	Cared for person also a carer themselves – mutuality/complexity	
	<u>Young Carers Group comments</u>	
	When started to attend secondary school – realise do more than other people of the same age	
	Don't know they are a carer until they become involved with the young carers service	

Have social care, health and other professionals in York recognised your role as a carer and do you feel you have been treated with respect by them?	Nothing but praise for them	2
	Been very well treated	4
	Caring & Coping course was a great help	3
	Alzheimer's Society helped and understood	1
	Yes	9
	Time to myself is a 'god send'	1
	No – upset over range of professionals' attitudes	1
	No – not supported early enough	1
	No – there are issues about also being the cared for's advocate as well as their carer	1
	Some - GP doesn't seem to understand, doesn't like carer attending with cared for	2
	Dementia Assessment excellent	1
	Yes, but very gradually – carer's needs not considered and person being cared for is seen as more important	1
	Impact caring has on carers' lives not always recognised	1
	Carers Assessment was invaluable	1
	<u>Other comments</u>	
	A number of individuals were named and praised for the work they do	
	Caring & Coping course invaluable but doesn't want groups as wants to get away from the condition the person being cared for has	
	Don't want too much respect – this would mean that wouldn't have been pushed to accept help	
	<u>Young Carers Group Comments</u>	
	Not really	
	Health professionals often do not speak to young carers even though they are often the ones who know most about the cared for's condition	
	Social workers and other professionals often visit when young carers are at	

	school so do not take their needs or views into consideration Schools don't understand Some individuals are great	
Who else in the City needs to be carer aware to make sure you get the help you need?	There should be a good liaison network – hospital, GPs, social services	2
	GPs should refer to social services	1
	Nurse at York Hospital was wonderful she contacted Age Concern and Social Services	1
	Not sure	2
	York Council very caring	1
	Nursing professionals and public need to understand difficulties facing carers	3
	Social Services	1
	Utilities companies (gas, electric, water etc)	2
	Refuse collectors	1
	Postmen	1
	Door to door callers	1
	People should be aware that dementia sufferers can live on their own	1
	General public	1
	Employers – consideration for carers is not the same as that given to parents	1
	Everyone	1
	Council Tax Offices	1
	<u>Other comments</u>	
	All staff should be aware of how to respond to the needs of the blind & partially sighted	
	Some Care Workers can be critical and don't seem to understand how hard it is to care for a dementia patient	
	Some Care Workers do not do enough	
Young Carers		

	Schools, GPs, healthcare professionals, external care professionals, external care agencies coming into the home, social workers Already registered with the Emergency Card & Warden Scheme	
What information do carers need?	Where to get help and advice How to deal with dementia in the home Caring & Coping course helpful How to get help as and when it is needed & who to contact for support How to claim benefits & what benefits are available Information pack from Social Services was useful An understanding of the condition of the cared for – both physical and mental Legal information Need publicity about where to go if need more information Help with getting equipment As much as possible Permanent, non-changing phone number for care services at the Council. Not an 0845 number. Out of hours a problem Dependent on individual case Attendance Allowance Council Tax Voluntary Sector Support Community Health & Care Workers Dementia Cafés Talking to carers informally Finances Availability of day care Availability of short term respite care Library Service Social meetings Don't know what you need or want if you don't know what is available	4 1 2 2 5 1 4 3 1 1 1 1 1 1 1 1 1 1 1 2 1 1 1 1 1

	Would be good to have annual visit to carers to check how things are A named person to contact for help What to do in an emergency or when something out of the ordinary happens <u>Other comments</u> Not always easy to find out what is available Knowing that you are not on your own Took a year to find out that I was entitled to a reduction in Council Tax What to do when a condition worsens Someone who will deal with non-personal care problems <u>Young Carers Group Comments</u> What support is available What to do if something goes wrong Who to ask Information isn't a major need for young carers	1 1 3
Have you managed to get this information?	Yes Not always No Gradually No because these services are not available <u>Other comments</u> GP was excellent at getting right people out to undertake an assessment Carers pack sent to me but dyslexic so carer support worker helped Lots of information given by social workers, nurses, occupational therapists and physiotherapists – very helpful	17 1 1 1 1

	<u>Young Carers Group Comments</u> This is not the most important need Can access information on the internet Peer and 1:1 support is more important	
If so, how and where did you get it?	Caring & Coping Course Alzheimer's Society Social Services Carer's pack Work colleagues Carer's centre Blind & Partially Sighted Society Council offices Through hospital admission Support from Care Workers Support from day centre Library Van – a CYC worker helped me fill in the Attendance Allowance form after it had been rejected twice Asking and listening to other carers Eventually through professionals and the voluntary sector Through GP Through Memory Clinic Nurse Age Concern <u>Young Carers Group Comments</u> Internet Family & friends Young Carers Service	6 5 4 1 1 1 1 1 1 3 1 1 1 1 2 1 1
Any other comments	Caring & Coping course is really helpful. Difficult to attend if need to care for someone (ok if it is on the same day as respite care)	

	• Would have preferred not to have lots of bits of paper, a book would have been better – know it's more costly. • Not listened to. Managing drugs is problematic, especially if there are lots of them • Care workers coming into the home need to be more hands on and need to realise that the cared for 'doesn't always mean what she is says' • Carers Assessment helpful but there doesn't appear to be any link between that and the Care Managers/Care Services • Carers asked to deal with things that are in the cared for's best interest without any regard for whether or not it is in the carer's best interest • Harmony Café needs more recognition • Care Worker pushed me to accept my limitations and ask for more help • Family and friends are very important and trying to keep being part of the normal world as long as possible • Often feel overwhelmed by the numbers of groups offering help • If carers could be referred by GPs to the Carer's Emergency Card Service where needs could be assessed and appropriate help filtered from the wealth of groups and services available • The support that both my wife and I have received has been first class and really appreciated • Admission to a medical ward in hospital if the patient has dementia is problematic – training in handling dementia required – little notice given to carer & no falls prevention. There was a delay in transfer from first social case worker (3 weeks) to second which leaves one in limbo at a time of crisis • Once a person is identified as a carer it would be helpful if the Doctor could hand out a pack providing basic information i.e. contacts for York	
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	Carers Centre. This would lead to a Carers Emergency Card Assessment of need by Social Services who could also provide advice on grants, benefits etc and link into Crossroads. Secondly information on the relevant condition/condition organisation would be useful (ie Alzheimer's Society, MS Society). Thirdly contact details for the local branch of Age UK who offer lots of advice and links to their support team In Safe Hands. Fourthly contact details for the Citizen's Advice Bureau who can provide information on residential homes and advice on paying fees • Information pack only received after 3 years & contained too much information for a new carer <u>Young Carers Group Comments</u> Information is not the most important need for young carers. They ask for support in school and support in their caring role such as a chance to talk, chance to meet others in a similar situation and the chance to be a child or young person.	
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