

**The Future of Carers' Services
Report from the Carers' Rights Day Forum**



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Carers' Centre Chief Executive**

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Introduction

The Future of Carers' Services was organised by the Carers' Centre Bath and North East Somerset in partnership with Rethink and Off the Record Young Carers Service, Bath and North East Somerset Council and NHS Bath and North East Somerset. Information stands were provided by Crossroads Care Wessex, Shaw Trust, Your Say, Family Information Service, Soundwell Music Therapy, ICAS, Well Aware and stands and break activities were provided by Give Us a Break.

Sonia Hutchison, Chief Executive of the Carers' Centre introduced the day and the key note speakers, Malcolm Hanney, Deputy Leader and Cabinet Member Resources Bath and North East Somerset Council, Chairman NHS Bath and North East Somerset and Angela Smith Group Manager Adult Care and Commissioning and Carers' Lead.

The Forum had 2 Workshops, one looked at the Future of Young Carers' Services and one looked at the Future of Adult Carers' Services with additional support for carers with learning difficulties through support staff and easy read documents.

Executive Summary

Adult carers main areas that are identified in this report are the need for:

- Person centred information, support, assessments and planning that is consistent and follows the carer and is followed up.
- Continued provision of flexible breaks.
- Emergency card scheme linked to an emergency service
- More information that is accessible and well publicised including about cuts and their impacts.
- Group and individual support including with benefits, greater support from the GP and better support for working carers and self funders.
- Training to support in the caring role, involvement and to navigate available support.
- Consistent quality, affordable, relevant and accessible respite care.

Future of Adult Carers' Services

Carers were asked to give their views on how services should be delivered for carers in the future. The questions were based on the outcomes of the national Carers' Strategy and focussed on the priorities of the local Carers Commissioning Strategy. Each outcome was focussed on for 15 minutes with groups of carers and rotated so each group of carers were able to give their views on each outcome. Gaining the views on each outcome was facilitated by professionals from the Carers' Centre, Rethink, Bath and North East Somerset Council and NHS Bath and North East Somerset and notes were taken of the carers views. These are collated below:

1. Carers will be respected as expert care partners and will have access to integrated and personalised services they need to support them in their caring role:

What this outcome means for Carers in Bath & North East Somerset

- Carers are identified, respected, and more importantly feel able to identify themselves.
- Carers and the role they undertake is valued by all agencies involved in supporting them.
- Carers can access flexible support and breaks to enable them to carry on caring.
- Statutory responsibilities towards Carers are met and Carers are involved in the planning and commissioning of services for the people they care for.
- Carers receive information about the options open to them and can make informed choices about the support they need.
- Organisations supporting Carers work together to provide personalised and culturally appropriate support
- Carers receive support relevant to their age, gender, race, disability, sexuality and religion and the nature of the caring role.

What services do you need as a carer?

- One individual said that as he was a new carer for his wife who had developed Alzheimer's, he was new to the role of a carer and felt overwhelmed with offers of support. He said that he needed direction and signposting on how to organise their lives. He felt that this was particularly important when caring for an individual with Alzheimer's. He found that a lot of people were willing to help but that this made him feel pressured and overwhelmed and he didn't know where to start. He felt that it was general day to day running of the house that he struggles with the most and that he is overwhelmed with the day to day tasks. He does not feel comfortable leaving his wife alone for more than one hour and so doesn't get much time to himself, as she needs to know that he is in the same room all the time. The idea was raised that there needs to be a person that can signpost you and who can provide you with the knowledge of what it is you need.
- It is important to be identified as a carer in order to access services as they are not offered to you on a plate. It can be emotional admitting that you need help and you can sometimes feel like you are failing.
- Need caring to be recognised as a role in society.

- Need transport. I.e. transport may be provided for individuals being cared for but not for the carer so have to find own way to hospital appointment for instance. Better transport, they drop you at door but not where you need to be for the appointment.
- Need an advocate, maybe a place where you can go to and they will sort out what is available for carers. Some carers know what is available already but time restrictions to do things, and they are too busy to follow it up.
- Need someone to look at needs and days to sit down and think what needs are. They felt that a carer's assessment should fulfil that role but that it doesn't and one carer had 3 sessions on a carer's assessment and nothing happened. It was filed away and not used and out of date, there was no action plan. Normally all they do is tell you things that you already know and they go out of date because things change all the time.
- Need time to organise yourself and need a person that can be there to support you consistently. Someone that you can rely on. This way you would not need a carer's assessment as there would be someone who knew what you wanted and would know you personally so wouldn't need to ask 'silly' questions. Carers need a carer or personal assistant type person themselves.
- Need one person with knowledge to go through all the information at once and make it more accessible. Carers felt there wasn't consistency and that there was more support from voluntary and community workers and not as much support from social care workers. They said that it varies between cases and areas some get more support than others. If your needs are not seen as immediate then you are taken off the list. They felt that this was 'no great loss' though as you will not miss this help as you did not receive it in the first place.
- Need to be able to access help when it is needed i.e. when in crisis and to access it straight away.
- Need to be treated with respect and believed when say you have problems.
- Possibly have a passport with information on that is important to the care of the individual to save you repeating information to lots of different people. Could be used for dementia etc. or learning difficulties. Something with a list of their needs on it.
- Need a voice and a focus, instead of professional people giving lip service and speaking on their behalf, need own voice.
- Need information and a central point to get it i.e. a centre and not social services or council etc. A centre that is part of everyday life i.e. a supermarket where you can go to get information or pick up leaflets and get numbers to ring for advice.
- Need good health care and GP service and support. BANES area is good for GP support, and kinder than social services and more supportive.
- Need a consistent domiciliary care service.
- Care workers coming three times daily to help with getting up/putting to bed/lunchtime.
- Meals on wheels/Wiltshire farm foods.

What times and days do they need to be provided?

- Every day!
- 24 hours a day and in the night especially. Someone else pointed out that this would be impossible and this is what we have the NHS ambulance service for and that we are already overstretched with resources. Pragmatically couldn't have 24

hour support, but that this is the social services duty of care. There should be an emergency number at least.

- 24 hours a day, just to have it there as a crutch and to know it is there if needed as security. Emergency respite care and not just the ambulance. Like NHS direct but more efficient and based around carers. Somewhere that already has all your information so that you don't have to answer the same questions all the time and every time you want help. A database where you only fill out a form once and details of your support needs and benefit details are all online.

Where do they need to be provided?

- In the home
- Perhaps centralised under one roof and know where to go rather than having to go to many different places.

How do they need to be provided?

- Face to face and not on the internet, even if this is a cheap way of doing things and saves money, don't want newsletters or having to search the internet. We want people as anything else takes too long and too much time.
- Needs to be provided through a personal contact who you can speak to on the phone when you need to, like a financial advisor sort of role, but a care advisor.
- In a centre with paid staff not voluntary, as need staff to be paid to get high standard.

What are the key points professionals need to know when they are trained?

- Listen.
- Don't make out like they know all the answers without listening to what the questions and needs are.
- Everyone is different and their relationship with the person they care for is different i.e. older or young carer. Every individual case is different.
- Be open to conversation and good at problem solving. Not too many letters to individuals. Not too much information given out at once as it is overwhelming. Information specific and useful and not too technical, much more simplified.
- Carers should have respect/support from all services.
- 'Care workers need to listen to the expertise I have and work with me and listen to me. The lack of continuity of staff meant the staff I trusted weren't always available. Continuity would have been much less stressful. It didn't help me at all for the wrong type of care worker coming to look after the cared for person. The person being cared for must be the centre/focus of the care worker, not housework.
- Agency staff who communicate well, ask what the carer/cared for need.
- 'Agency staff have got respect for my dad which I like'
- Friendly care workers who take time to talk with the cared for person.

What information and in what format is needed to ensure technologies such as telecare and telehealth are used more effectively to enable the cared for person to be more independent and the carer to be more supported?

- Don't want technology. Want a person to speak to face to face and to signpost where help and support is.

How do you want to be involved in future decision making? And what support do you need to do this effectively?

- Representation on strategic boards and local government health boards. Be paid to go and represent your corner and have a voice.
- Have group meetings and get feedback from frontline.
- Need training to understand what the issues are with the person you are caring for i.e. in mental health so know exactly what person needs.

2. Carers will be able to have a life of their own alongside their caring role

What this outcome means for Carers in Bath & North East Somerset

- Carers have time for themselves and 'a life of their own'.
- Carers are able to participate as citizens in their local communities and access the full range of universal services, including leisure and social activities.
- Carers are able to take up training, employment and volunteering opportunities.
- Carers feel confident that in the event that they were unable to care there is a plan for how the cared-for person will be supported.

What respite would help you be able to take more breaks etc

- Domiciliary care services need to be better. Outsourcing of care cover not working as quality not consistent. I.e. double medicating
- Direct payments come with the problems of outsourcing and getting quality care.
- Length of break provision short so constantly thinking "I've got to get back spoils the break
- More breaks- People love the give us a break scheme and are worries about its longevity.
- Companion needed to keep cared for person occupied.
- Day centres not flexible enough for younger people.
- Cared for persons befriending could be developed more
- GUAB wonderful and life changing.
- Day care good but transport was a problem until carer took over the transport.
- Home care was a good way of having respite.

Barriers to respite

- Time
- Cared for person doesn't accept replacement care
- Cared for person is resentful and gives you a hard time when you get home, making you feel like they have struggled and judging you for having "you" time. -jealousy
- Giving yourself permission to have a break/
- Cost is a key barrier- £12.00 an hour or more and people aren't always aware of cheaper alternatives.
- One hour doesn't give you enough time to have a break. Having your replacement care paid for, like with Give us a break" is imperative
- Need to be encouraged to have a break for one to one advice and counselling.

Concerns again about quality and cost of replacement care.

Emergency Planning

- A carers emergency scheme is desperately needed.
- Others use an alarm system
- Life line alarm
- Key safe

What breaks would you like?

- Trips away
- Be active
- First aid course

How could carers assessments be made easier for you?

- One in three of the group had had a carers assessment
- Need to have it explained properly what it is about

3. Carers will be supported so that they are not forced into financial hardship by their caring role

What does this outcome mean for Carers of Bath & North East Somerset

- Carers know where to go for information and advice.
- Carers will have access to information and advice on income maximisation.
- Carers will be supported and enabled to choose to remain in, or return to employment

What information and advice is key to you being able to continue to care effectively and maximise income?

- Good accurate information about changes to benefits to carers and cared for
- Publicise that GUAB ends in March
- Updates on how the cuts will affect carers
- Good information about what will happen and when
- Issues around Carers Allowance and the inability to claim if in receipt of other benefits
- How to get help to fill in forms and appeal against decisions if necessary
- Well informed, 'expert' staff to support carers to fill in forms
- Knock on effects of carers benefits being reduced if cared for benefits increase
- Follow up to ensure that signposting is effective and that results are good for carers
- Good information about changes to benefits
- Up to date information about new local and national policies and resulting changes
- Reluctance of carers to apply for benefits because of the time factor and the frustration around the whole process
- Need for a carer's 'personal assistant' or 'keyworker' who can facilitate the implementation of the action plan from the carer's assessment
- Expert help from well trained staff who know their subject
- The impact on the applicant can be high
- Independent provider of the keyworking role
- Help for emergency planning
- Why so many questionnaire's?
- Big financial impact for self employed as variation in care can impact on amount of work completed
- Inequality of carers allowance
- Recognition of carers - why no carer's card that is recognised by all
- Training issues about what is available
- Benefits advice, someone to check that I am receiving all the entitlements.

How do you want to receive information and advice? Leaflet, web, in person, phone, variety

- Accessible
- Easy English
- Less jargon
- No acronyms
- Personal touch

- Flexibility to understand and meet needs
- Easily understandable
- Home visits when replacement care can be available
- Expertise to help carers make an informed decision
- Reviews and recommendations
- Address issues around self funders
- Appropriate to each individual carer
- Better marketing of carers services - regular update in Council Connect
- Better expert financial advice
- In person - definitely. Don't like talking on the phone about these matters.

What support do you need to return to work or remain at work if that is what you want to do? And what support do you need to make a complaint if things go wrong?

- Supporting working carers when day services are cancelled
- More availability of day services
- Carers assessment should have greater emphasis on working carers rather than those who are financially eligible for services
- More holistic approach
- Emergency planning - bigger focus on both working and non working carers
- Lifestyle planning - good example as used by Somer Housing
- Emergency planning - how do providers adequately match the individual response to caring
- Need for more appropriate day services for younger people with dementia and Alzheimer's Disease
- Good, reliable, consistent replacement care
- More flexibility around the provision of day services
- Employer to be more patient - lack of understanding on employers part.
- Union support.

4. Carers will be supported to stay mentally and physically well and treated with dignity

What this outcome means for Carers in Bath & North East Somerset

- Carers feel more supported to be able to carry on caring.
- Carer stress is reduced and their mental health is improved.
- Carers physical health and self care is improved
- Carers will be treated with dignity and respect

What specialised services do you need to continue caring?

- Breaks (with and also without cared for person) *Stress management through holistic approaches (e.g massage)
- Breaks within the BANES area rather than in Soundwell etc
- Day care that is tailored for the cared for persons needs (e.g a lady at the forum was caring for her husband who had Alzheimer's but was only in his 50's. The services available to them were not tailored for younger people with the condition)
- Someone to advise on time management and day to day running of the home carers expressed that they were overwhelmed by the tasks of running the home and caring at the same time
- Health checks at GP practice.

What online support would you want to have online?

- A clear and concise website with links to support services in the BANES area
- An online resource which would enable carers to interact with health professionals and other carers
- Hard copy literature in the form of a booklet (advising of support services) would be preferable
- It would need to be easier to understand to be useful.
- Costs involved in using during the daytime.

What emotional support services do you want to receive?

- Group meetings with other carers to enable the carer to feel less isolated and be able to receive emotional support from those in a similar situation
- Someone to be able to go to for advice (e.g someone who can direct them to appropriate services)
- Consistent and regular assessments in order to capture any changes in the carers emotional or stress levels
- Art group at Carers Centre (Carers for Each Other)
- Other local groups.

What support do you need from your GP?

- For the GP to be aware that they are a carer
- For the practice to automatically send them letters inviting them to have a routine Flu injection etc

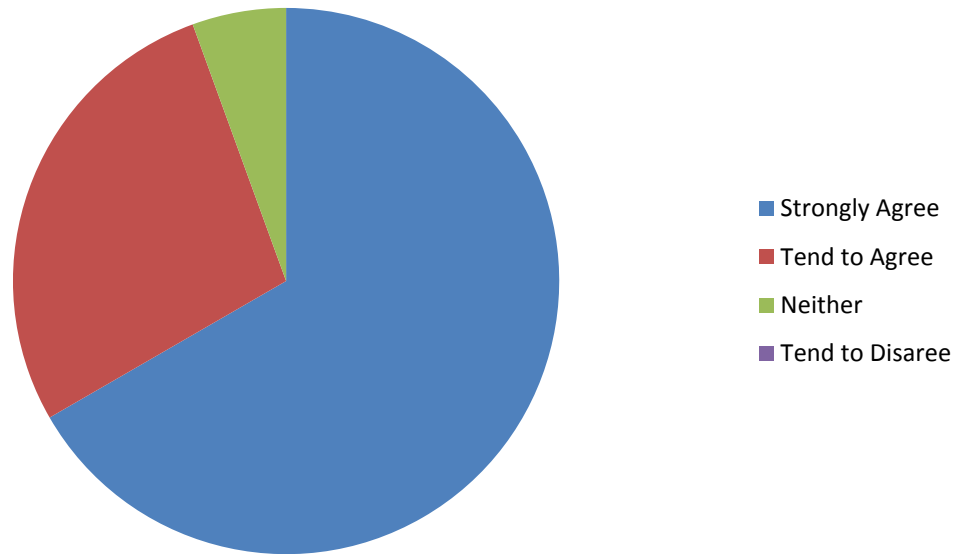
- To be able to discuss concerns with the GP about the cared for person (a running theme throughout the conversation were that because of data protection some carers were able to get the information they required from the GP).
- Being accessible out of hours.

What training do you need to develop new skills?

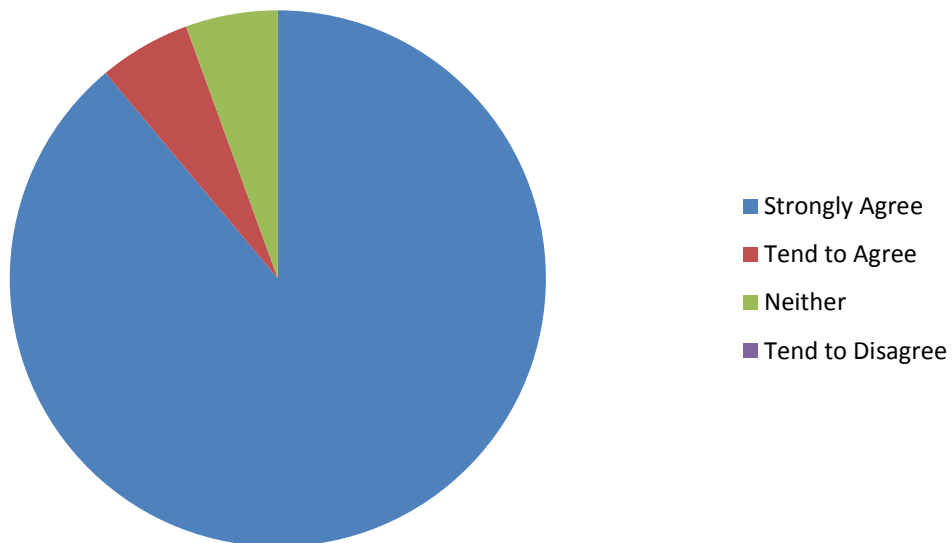
- An understanding of the multi agency working
- A service pack for carers (a directory of volunteers services in the BANES area)
- Confidence building workshops

General Feedback

The Aims of the Event were clearly explained



I felt my views were listened to at the Forum



What did you think about the different activities that were available during the Forum?

- Interesting and varied. It was good to chat to the leader of each activity and catch up on news since the previous event.
- Very useful thank you
- Very informative
- Very good-very helpful
- Very good
- Interesting
- Fine

- Good range, fun useful
- Informative
- There was a wide range of activities meaning everyone was engaged busy and interested
- Very good and interesting- good variety
- Very informative/would have liked more time
- Very informative
- The young carers activities were excellent

Do you have any comments about the venue, catering, timing of the event or the Forum itself?

- Very comfortable and relaxed atmosphere-we were very well looked after.
- Adequate but more space would have been good
- Warm and comfortable
- Wonderful
Everything was fine
- A pm timing would have been better
- No comment-can't complain
- Very good-I enjoy buffet lunches. Timing is good
- Catering was good and plenty-very good venue and fairly accessible
- Out of school hours would have been better for young carers
No it was very good
- Good and easily accessed
- Very hot as sat in the sun
- Better directions needed. Food okay
- Everything excellent
- Hard to find-ran out of chips

Are there any big issues facing carers that we have not discussed today?

- I am concerned about hidden carers that can't make these events
- Just information
- Re assessments with DWP
- Carer's information packs
- The carer's role etc. is impossible to be covered in one forum
- Negotiating benefits system

Do you feel that the forum is the best way of finding out carers' views? If not, in what other ways do you feel we should be enabling carers to have their say?

- Yes/Yes/Yes/yes/yes/yes /yes definitely/yes very good/Yes if care cover is paid for.
- It's a good way of finding out views and its helping me to mix with other carers
- It was good- but maybe we should have had more introductions so we knew who else was attending
- Yes first time at one- pleased someone actually listened to me
- Yes it is, also through surgeries, doctors and the local papers
- I think this is a very good initiative
- This was invaluable and has really helped the young carers.

Additional Consultation

The Carers' Centre recognises that not all carers are able to attend an event to give their views and sent out a questionnaire by post to give carers an opportunity to give their views about the future of carers' services. The questions were simplified and only focussed on what the perfect Carers' Centre should provide. This was sent to over 900 carers and the results are collated below:

What services would you like the perfect centre to provide?	When would you like it to be provided?	Where would you like it provided?	How would you like it provided?
Cover for when I need to go out	Day and evenings	Bath	Face to Face
Information	Day - drop in sessions - flexibility	Bath	Phone and all forms of communication
Easy to contact when crisis hits the family which can happen anytime	Daily in the mornings	Locally easy to get to	Face to face
More carers' forums - good opportunity to meet fellow carers' in very pleasant venues	Daytime 10-3pm	Venues are good now	Face to face, telephone - staff are always very helpful
A place to bring mum with me so we can enjoy quality time together. Have coffee/lunch speak to professionals. Listen to interesting talks/slideshows/music/film/hobbies/gardens	Daytime 10am-4pm or shorter 2 hour slots	Happy to travel to location e.g. Ammerdown, Saltford Golf Course, Anywhere local gardens/parks	Face to face, smallish groups
Something for young carers during school holidays			

<p>A place to go for advice, help, help filling forms, a library of useful information. Carers breaks, a place to go and do activities with the cared for person. A place for disabled children to meet and play safely. Support activities for parents of disabled children and their siblings. Toy equipment lending, access to services like speech and language therapy, counselling, one to one play therapy etc.</p>	<p>Different types of carers at different times. During the day for pre-school disabled children. After school for older disabled children 3.15 younger ones and older ones later. Weekends for dads and families. Not having lots of teas/coffees around when there are children</p>	<p>Most parent carers are used to travelling to access services - so not that important. Bath (the hut?) Fosseyway School. 3 ways school.</p>	<p>A place to go with disabled children & meet others and do normal things. Maybe also information on website/ postal lending (inc. toy) library. People to come and talk to you if you can't get out.</p>
<p>A telephone contact for my son who has Aspergers Syndrome for about 3 weekends a year when we go away</p>	<p>3 weekend Sat/Sun Day and evening for son to call if he's in a panic</p>	<p>Peasedown St John</p>	<p>Telephone and access to plumber/electrician.</p>
<p>More financial and legal advice for people who are not eligible for welfare benefits</p> <p>More advice on care home options including appraisal of local options (CQC is too formulaic)</p> <p>More fun things to do with other carers</p> <p>Access to education/training/work opportunities</p>	<p>At least one late night opening/telephone help line per week</p>	<p>Bath</p>	<p>Ideally face to face and telephone - web's a bit boring, emails ok as long as people respond.</p>

Breaks, mini holidays. Just to get away for a couple of days to unwind and refresh. Caring is 24/7 52 weeks a year. It's mentally exhausting	Now	Anywhere within the South West	Hopefully free or a small fee like 300-500 a week. Just to relax body and soul.
Carer support Carer support groups Information esp. benefits Ideas for how to manage Mediation, counselling Campaigning for carers - local and national Local support to reduce isolation	I would prefer day time but evening for working carers	B&NES is spread out, the Carers' Centre should have local surgeries and support groups Particular support workers for each area - someone who can be a focus and organise local events/social groups	All of these maybe a local internet forum would be helpful - as long as it was controlled.
Monthly Meetings for carers to get together and support each other just for a social setting	Weekdays working hours	Carers' Centre, Local Hall, Bath	Face to face, I feel most of us are aware that we have a friend at the end of the phone.
Clear, understanding information I require		Bath	Face to face

Friendly and relaxed			
A coffee and a chat for anyone who has problems	Daytime 10-12	Bath, Radstock or Midsomer Norton	Face to Face
Transport with helper to shops and assistance there	Mainly mornings according to reaction to pills	Bath	Face to face on helpers visits
Information on local services & welfare rights Counselling of individuals Drop in Centre for coffee/lunch open for 2 hours a day Seminars to discuss specific issues Training in certain aspects of caring	Midday - 4pm Mainly because one is often taken up in the morning getting the carer for person "launched"	In a venue which is accessible to Bath & which has it's own parking. Time for carers is often short and the stress of having to search for parking can put people off going to events offices	Telephone is very useful Face to face allows for productive discussion to take place.
Counselling Information on all aspects of care Drop in sessions for carers' mutual support	Week days and weekends All reasonable times	Somewhere with easy access by car and parking on public transport	Face to face, telephone, internet & skype and video link for those unable to travel.
Please ask Chew Magna Surgeries	AM quite	Quite	Face to face

<p>to offer carers health checks.</p> <p>Money to go to classes, gym of choice</p> <p>Professional to meet who understands particular issues</p> <p>Counselling individual and couples</p> <p>Talks on relevant issues</p> <p>Evening/weekend support phone line</p>	<p>flexible</p> <p>Need notice to plan</p>	<p>flexible</p> <p>Bath, Midsomer Norton, Keynsham, Chew Magna</p>	<p>ideally</p> <p>Internet</p>
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