

“The True Face of Carers”

MPs and Carers event in Kingston

11am – 12.30pm

Friday 10th June

Queen Anne Suite

Guildhall

Kingston

KT1 1EU

Agenda

10.30am **Coffee and registration**

11am **Welcome and introductions** – David Smith

An overview of Coalition Governments policies and priorities for carers - Ed Davey and Zac Goldsmith

Messages from carers:

- what works well for carers locally
- what doesn't work or needs improving locally
- gaps in local services and support for carers
- carers views of the Government's policies and priorities with messages for the MPs to take back to Westminster

Questions

Next steps

12.30pm **Refreshments**

Messages from carers

What works well for carers locally

"Kingston has a number of support networks namely the Dementia Carers' Café, the Kingston Carers' Network and Age Concern. Social Care Services are also extremely supportive."

"Kingston Carers' Network has evolved. MENCAP and other specialist carers groups are very good."

"Kingston Carer's Network."

"Addiction Support and Care Agency (ASCA) is an invaluable service for carers of people who misuse drugs and alcohol."

"The staff at the centre are very understanding and approachable you always feel that you have someone to turn to who can help. Also the shop with the disability aids on site will be a great help when my husband's condition gets worse. It is also good to have a place where I can meet other carers."

"The respite provided by the borough is a boon."

"There are lots of activities going on, very useful and helpful."

"It is vital that good services remain and develop to support the service user - this is always the best way to support carers."

Messages from carers

What doesn't work or needs improving locally

"Provision of transport to various events organised by the various networks. If an extra minibus and driver was provided for the use of Alfriston to carry users, this same transport service could be called on to take carers, and those they care for, to network events at the weekends and in the early evenings. This would make best use of this transport service. Maybe the transport service could also be used for trips organised by Social Care Services too."

"Shorter waiting lists for diagnosis - I waited 2 years. More support and advice whilst waiting for diagnosis."

"More sibling support groups."

"More activities in-borough for autistic people are desperately needed ie soft play, autistic-only swimming sessions at the borough's pools, autistic-only cinema and theatre events, more play facilities, play-schemes, etc."

"More support for working parents, i.e. childcare, breakfast and after school clubs, and more pressure on companys to offer flexible working hours for parents and carers."

"Support and information groups for parents of disabled children are good, but often at inaccessible times."

"Do not cut the budget for people with disabilities - they are the hardest hit and they find it hardest to make up as they don't earn any money and find it all but impossible to do so."

"I do not drive so a centre or some events in Surbiton would help."

"More 'funded carers support groups' or a contribution budget offered to help those who run them independently and successfully now to help with costs."

"Although I live on a pension, I contribute towards my own specialist counselling and peer support group. Recognition and funding for services such as Addition Support and Care Agency (ASCA) would enable them to continue providing these invaluable services for carers."

"Staff in statutory services could learn a lot from ASCA. Carers describe the attitude of staff as being like having a 'door slammed in your face', being told they can't talk to them because of confidentiality. So, although no advice, support or information is given, the carers are still the people left to provide day to day care and pick up the pieces when things go wrong. Please treat us as the partners we are. Remember, we are all working towards the same goals."

"I hope Kingston Carers' Network can get a bigger at the Noble Centre to have more / larger rooms for events to take place."

"I think carers need more support and more time for themselves."

Messages from carers

Gaps in local services and support for carers

"Legislation is needed to stop the postcode lottery, with local authorities refusing services available elsewhere ('we don't do this in Kingston'). Government guidance has limited use, as Local Authorities simply ignore it. There should be more accountability.

In case of obvious physical disabilities, a Special Educational Needs Assessment should begin at the age of 2, in accordance with existing legislation. The current tendency at RBK to delay this process is harmful to children, as it diminishes their prospects of accessing Early Years education at the age of 3.

Also, social services in RBK should follow government guidance in providing a key worker / lead professional to help families with coordinating and accessing various services."

"Activities are good, but if you don't have transport or a lift, or you have health problems, you can't make use of them."

"The provision of an extra minibus, together with a salaried driver would be wonderful."

"Can anything be done to help carers get appointments sooner at the GP surgery? You can't see a particular doctor, and they don't come out to see you at home, even if one can't go."

"Mental handicap covers varying disabilities, varying needs - some have independence, some cannot. You are not taking this into consideration with these changes."

"So far support has been very good but now we are all at sea with no Causeway, no transport and a budget we do not want to have to worry about - we have enough to worry about. Remove this worry, please take the pressure off us carers. We need a Causeway, we need our transport, we need things as they are NOW. Our sons and daughters do not understand change – especially of this magnitude."

"My fear is that with the move to Individual Budgets for people with learning disabilities and the choice and opportunity to access community opportunities, we will be losing a streamline service that incorporates transport. The day will become disjointed and rely even more heavily on carers overseeing and making sure it works, picking up the pieces when it goes wrong, putting more pressure on carers, particularly those older carers, and will have a big impact on their lives."

Messages from carers

Carers views of the Government's policies and priorities with messages for the MPs to take back to Westminster

"Please remember those less fortunate than you and help them in their hour of need. Dementia is a growing problem and we need to have excellent systems and processes in place now as we handle the tip of the iceberg."

"Ring fence any money that the disabled are entitled to and consider them most because they are the most vulnerable".

"Carers make a really valuable contribution I believe need increased support for themselves, and possibly other members of the family. It can be really difficult for the entire family."

"The re-grading of Disability Living Allowance has not been thought through (like the NHS). It is time for a moratorium of this exercise too. If I lose my Carers Allowance, can I go on holiday without fear of charges for criminal neglect?"

"Stop making such drastic cuts in health and social care"

"Make paid work a reality and make it work for employers, the tax man and the benefits office too. At the moment it is a series of negatives adding up to a big negative'. Local authorities spend billions of scarce resource keeping people with learning disabilities inactive when a few less billions could benefit people with learning disabilities more by being included in the work place and you could do away with half the professionals cost and probably half the benefits costs."

"Carers work so very hard caring for their family member and carry such a huge responsibility, saving huge sums of money for the government, and it does seem that they are taken advantage of at every opportunity with even more pressure heaped on them with all the cuts and changes"

"Mentally handicapped people cannot get better they are most vulnerable members in our society, please, please look after them properly and give their parents the support and recognition they truly DESERVE."

"For many once disabled - always disabled. Moving the goalposts doesn't take away the need for carers."

"Care of older people in hospitals needs to improve. Staff at the local hospitals weren't helpful, I had a bad experience with my mother. I hope you can do more for NHS and dental appointments"

"Ask Maria Miller and her junior ministers why they couldn't send a representative to the *hardest hit* march - thousands of people who find everything harder due to disability bothered to go - but not our Government. Labour sent an articulate shadow - Liam Byrne"

"I have cared for my daughter for 41 years. I want to continue to do this but I need the support I have now - I ask for nothing more, but PLEASE NOTHING LESS!!! You will need more homes and hospitals for parents!!"

"Parents/carers of disabled children feel that for the authorities "a child is not recognised as disabled until he/she is 5". Disabled children of pre-school age need special provision (including educational) in order to access services available to their fully abled peers. Current legislation doesn't seem to put enough pressure on the Local Authority to secure appropriate funding and provide support for young children with disabilities, especially at the Early Years Education (nursery) stage. Disabled children, classified as "children in need", really need help. Please make sure that Government's Green Paper on Special Educational Needs addresses problems of disabled children with accessing nursery education (esp. mainstream)."

"Without help from the charities, it would be impossible to be a carer and remain sane. With so many charities struggling, government may have to take more responsibility for supporting carers and their families."

"Carers lives can be overwhelmed with anxiety. What we need are services that teach us how to look after ourselves."

"Please continue the funding to local authorities to continue to fund this service"

"I am bitterly disappointed with the Government's plans to cut back on services for one of the most vulnerable groups in society. Where will it all end?"

"Care enough to help the carers."

Questions

Q1 "Where has Ed Davey been with all these consultations going on about the Causeway closing?"

Q2 "I'd like to know more about changes being made to day services and about transport to and from HFT Causeway drop in and respite care"

Q3 - "Why is the Council shutting the Causeway without any alternative put in place or planned?"

Q4 - "How can the Government help people with learning disabilities into work? In particular how can they make the balance between earning money and losing benefits better for the person and how can they help all employers benefit without additional cost to their business in terms of support the person will need?"

Q5 - "In the light of the many people with disabilities (in particular those with learning disabilities) are now, due to modern medicines and treatments, are enjoying a much longer lifespan, into their 40s, 50s and 60s, what does the Coalition Government intend to regarding the provision of their care?"

Structured all day Day Care Centres provided very well for their care, affording the very necessary respite, for their elderly parent carers, in order to keep sons/daughters at home.

With the demise of Day Care Centres, elderly parents will no longer be able to care for their adult children, and have no alternative but to put them into care homes, much earlier than was necessary.

Here in RBK elderly, parent carers will, very shortly be experiencing this problem, as the closure of 2 Day Centres which have proved to be a lifeline for carers & users for over 25 years, are about to be closed. Some of the elderly parent carers, who themselves have age related health problems, will have to face one of the most difficult decisions of their lives.

So, has this Government got alternative plans in answer, to what will be an ever increasing problem Nationwide? if not, then we will be turning the clock back 50yrs to the days of the 2000 bedded institutions to accommodated out vulnerable adults - and that is NOT acceptable."

Q6 - "What support and re-assurance can you offer to carers that with all the cuts and changes locally that there will not be even more pressure put on carers?"

Q7 - "Government provides 15 hours of free Early Years Education for all 3 and 4 years old, to give all children equal opportunities. If Local Authority has no legal obligation to provide equipment, assistance and transport that pre-school disabled children need to access education, those children are excluded from the vital services available to healthy children. How can we avoid this discriminatory practice?"

Q8 - "Good respite is offered and an invaluable Family Support Service. However, many people who desperately need these services are not getting access to them because of cut-backs. What do you propose to do about this?"

Q9 - "Will the level of funding continue to enable us to keep this excellent service? I ask as a person who thirty years ago had to care for elderly parents both with physical disability with no help at all, so I appreciate the help now."

Q10 - "More support for working carers. What are their commitments?"

Q11- "Increase in Carers Allowance. Are they in agreement?"

Q12 - "In what way do they envisage local services developing?"

Q13 - "Dementia sufferers and their carers are usually from the older generation and have a major challenge when it comes to transport. For example a Dementia sufferer cannot travel on their own by dial-a-ride.

The taxi card system is also very hard for a Dementia sufferer to handle as they have no short term memory. The Alfriston Centre provides a wonderful service of care for the sufferer and respite for the carer:

Could we please have some funding so that more transport can be provided? Currently there is a queue to get access to transport to and from the Centre and the transport does not pick up users until late morning and drops users off in the early afternoon which does not give much of a break to the carer.

Q14 - "What is the logical thinking in relation to cancelling carers' allowance, to cancelling disability allowance? The disability lives on."

Q15 - "How long is the waiting list for Council Houses? Someone has been waiting for 20 odd years."

Q16 – "To ensure that staff who provide care and services to people in their own homes, come for the times they have been employed to, I think local or central government could consider introducing a GPS system. What are your views?"

Q17 - "In light of last week's Panorama report, what response or measures are the government putting in place to safeguard some of the most vulnerable people in society?"

Next Steps

A summary report of the event will be produced and circulated to all participants by email or post and the report will be added to the Council and Kingston Carers' Network websites.

As part of the Next Steps, you may want to come along to

The launch of the

Kingston Carers' Forum

Kingston Carers' Network and Adult Social Care Services are proposing to set up a Carers' Forum in Kingston which will enable carers to have a stronger voice in the services and support for them and the people they care for and to be better represented across the borough.

If you would like to be involved or would like to find out more about this please come along to the meeting at

1.30pm

Wednesday 29th June

Noble Centre

109a Blagdon Road, New Malden KT3 4BD

Refreshments provided.

Contact Kate Dudley on 020 3031 2757 or email
admin@kingstoncarers.org.uk

Thank you for coming