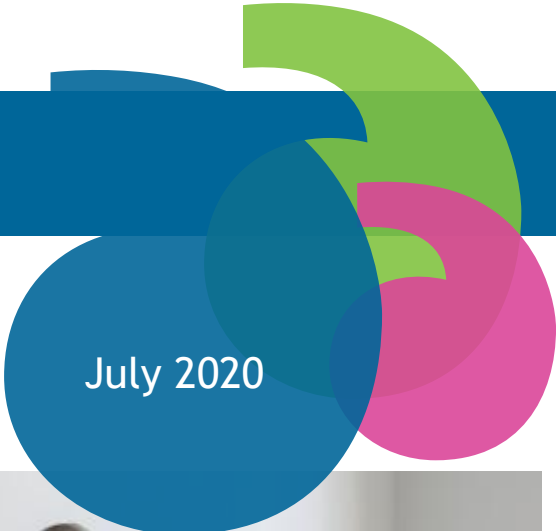


#MakingCaringVisible in Rutland



July 2020





Contents

Introduction.....	3
1. Method	3
2. Themes	3
2.1 Welfare calls.....	3
2.2 Access to healthcare services	4
2.3 Direct payments.....	5
2.4 Other themes: lockdown related	6
2.5 Other themes unrelated to Covid-19	6
3. A carer’s story	6
4. Learning points and recommendations	7
5. What’s next?	9
6. About Healthwatch Rutland	9



Introduction

During Carers' Week¹ (June 8-14 2020) Healthwatch Rutland attended an online 'surgery' with Alicia Kearns, MP for Rutland and Melton, to discuss how carers in Rutland have coped during lockdown². Attendance at the online surgery, was by its nature limited in number, and we wanted to broaden the discussion to other carers in Rutland who might be interested in sharing their experiences. This short engagement report provides an update on the feedback given by carers during the MP surgery on 9 June and the two further informal virtual 'carers' café' chat sessions on 26 June and 1 July 2020.

1. Method

As a follow-up to the virtual MP surgery two virtual meetings were held using Zoom, one for carers looking after people over 50 and one for carers looking after people under 50. The over 50's café was held on 26 June in collaboration with Age UK and the under 50's café was held on 1 July in collaboration with the Rutland Rotaract Family Support Centre.

The café sessions were informal chats, without agendas and with just three areas of discussion suggested at the beginning of each chat:

- How well carers had felt supported during lockdown
- Their experiences of accessing healthcare services during lockdown
- Anything else they wanted to communicate regarding health and care services

Carers experiences were the grouped into the themes below:

2. Themes from discussions with carers

2.1 Welfare calls

During the lockdown, several agencies were making telephone calls to people known to be vulnerable, isolated, carers for others, and so on. Known variously as 'check in and chat' or 'welfare calls', these were made by local council staff, charities, GP practices and NHS volunteer responders. Carers in Rutland spoke of mixed experiences of receiving such welfare calls.

One carer has 2 school age children with Education and Health and Care Plans and had received 2 calls from the Special Educational Needs case worker and also one from the

¹ Carers Week is an annual campaign from [Carers UK](#) and ran between 8 and 14 June 2020 with the handle #MakingCaringVisible

² Lockdown: from 23 March 2020 people in England were instructed to stay at home, leaving only to shop for basic necessities, exercise, attend medical appointments or to travel to work if they were key workers. The Government began to ease lockdown restrictions on 1 June.



Council’s Aiming High team³. She felt it was reassuring to be on their radar but other than that, did not get much out of the calls. She felt the children’s school had been much more supportive in practical ways, providing work and suggesting activities. Another carer had received a welfare call from the Brightways⁴ team in early June, but no action resulted from the call. She felt it had been something of a “tick box exercise” and Brightways had remained closed with no support sessions on offer. Subsequent to the café meeting the carer was contacted by a member of the Brightways staff regarding support for her son through accompanied walks. This was welcomed, but the carer felt that virtual support could have been offered much earlier during lockdown.

During time at home whilst in lockdown, another carer and her child had ongoing welfare contact from the residential provider where the child is usually placed, via virtual therapy calls. These regular calls were very well received and provided some continuity during a time that was difficult and confusing for the young person.

A carer who looks after her parents reported receiving a call from an Admiral Nurse⁵ in April, but had received no further contact since, from either the Council or GP surgery staff. A monthly call or email would have been very much appreciated.

Another carer reported feeling reassured by receiving a call from a member of the Council staff asking specifically about how she herself was coping with the lockdown.

An older carer whose partner has a long-standing Alzheimer’s diagnosis had received no welfare calls during lockdown, although the carer believes that she and her partner are known to the Council’s Carers team and their GP surgery. Again, she would have found a call useful and reassuring. A further 2 carers reported having received no welfare calls at all.

There was consensus at the 1 July café meeting that the term ‘welfare call’ carries a negative connotation of being ‘checked-up on’. Although not perceived as a major issue, it was felt an alternative term would be better.

2.2 Access to Healthcare services

One carer had several healthcare consultations by phone with their GP practice and a clinic for her children, and felt they worked well. In another instance she had a face-to-face consultation at a Cambridge hospital which also was straightforward.

Another carer had collected medications for her mother who was shielding, with no problems.

³ The *Aiming High* team, run by Rutland County Council provides support and activities for children and young people with special educational needs or disabilities and their families.

⁴ *Brightways* Day Centre is a facility run by Rutland County Council to provide activities and support for adults with learning disabilities.

⁵ *Admiral Nurses* are specialist dementia nurses who give practical and emotional support people with dementia and their families and carers.



A carer who was very ill herself at the start of lockdown had much praise for the care and attention she received from social workers and her GP surgery, working together, when she was unable to care for her adult son.

One carer's child had left her long-term residential placement for 12 weeks during lockdown to be cared for at home; the local GP surgery had 'been fantastic' in registering quickly and organising necessary medications for the arrival at home. A dental practice in Leicester sent a prescription for special toothpaste through Royal Mail which could be dispensed locally in Rutland.

Another carer is looking after her husband who has symptoms of dementia and who was due to be assessed at the Leicester Memory Clinic in late March. The appointment was cancelled and there had been no further contact for rearranging it. This carer talked of having no experience of dementia and feeling very anxious and 'out on a limb'. She is aware of the Admiral Nurses through her connection with Age UK but had not had any support upon which to draw (we assume until a diagnosis had been made). The GP surgery could not help about the missed appointment when she asked. The carer talked about her connection with Age UK as being 'a lifeline' during the pandemic. Age UK and Healthwatch Rutland took actions from the session to draw the case to the attention of the Admiral Nurses and follow-up the appointment with the Leicester Memory Clinic respectively.

Delivery of medications has not been an issue for most of the carers, except in one case. This carer had already signed up, before the crisis, for the annual delivery option from Boots the chemist for her parents' medications. The service had been excellent until very recently when a delivery was missed, and the carer had to get quite assertive with Boots to get the situation rectified.

A carer who looks after her vulnerable parents had received no contact from the GP surgery at all to advise whether her parents should be shielding or not and she had to do her own research to work out how to best look after them. She felt that some advice from the surgery would have been welcome and useful and this weakness in communication is something that she would like to see improved.

2.3 Direct payments

During the virtual MP surgery held in mid-June, several carers expressed disappointment that they had not been able to use their direct payments as flexibly as they would want and, as they believe, they should be able to do. For example, pre-Covid-19 funds set aside for a specific support group or activity may not have been spent when the activity simply stopped during lockdown. Carers talked about Rutland County Council staff refusing their requests that they be able to use the money to pay other providers who may have set up something similar, but online, that their cared-for person could access.

By 1 July, a carer at the under 50's café reported that she had very recently been able to switch payments in a flexible manner after she had followed up the same issue with Rutland County Council.



2.4 Other themes - lockdown related

1. Most carers had not put into place specific back-up plans for keeping their loved ones safe and supplied, if they were suddenly taken seriously ill themselves.

Healthwatch Rutland took an action from the older carer's café to supply links to helpful resources for carers, templates for emergency grab sheets and communications passports, and the Rutland County Council crisis number to be kept close to hand.

2. One carer's children were getting back into the routine of school by the 1 July and their 1-to-1 support at school was already helping them settle into positive routines.

This comment brought general agreement from all the carers at the session for under 50s that speed of restarting support activities/sessions was important. Their loved ones have largely got used to very restricted lives and the longer it continued, the more difficult it would be to get them used to going out again.

2.5 Other themes - non-Covid-19 related

1. One carer highlighted the difficulty in getting support for children under 5 in Rutland. What is available through the Visions Children's Centre requires the parent carer to be present at the sessions. This offers the carer no respite break from the caring role - something that carers of under 5's desperately need, particularly when they have other children and family responsibilities to consider. Another carer was concerned that, when at breaking point with an under 5, carers had reached out for help and had then become the subject of suspicion from social services that they themselves were the cause of the difficulties.

2. Several carers at the MP surgery drew attention to the stressful nature of the process for challenging Education, Health and Care Plan (EHCP) assessments and provision of care packages, for people with special educational needs. In Rutland the carer faces a barrister at the tribunal hearing, which is considered to be intimidating and unfair to someone who is undefended.

3. A carer's story: My Life March to June 2020

One Rutland carer documented her story, below, giving a powerful reminder of how much of a difference an integrated effort from different services can make to a family that finds itself in a vulnerable situation.

“For about 2 weeks prior to the Lockdown on 23rd March I just did not feel at all well.

It started with the loss of taste and me checking food labels as I thought they were all out of date. On a Saturday in March I collapsed in my local shop. The staff were fantastic, supporting both me, and my younger son who has Down's syndrome, autism and no understandable speech, until a family member came to collect us.

Once home I felt better, but on Monday I made an appointment at my GP practice as I still felt unwell but did not know why. The GP told me that I had a fever, that it was not Covid-19, and I should drink lots of fluids. The following Friday I went drastically downhill



such that my eldest son had to take time off work to look after me as I was completely incapacitated, in a semi-conscious state.

A friend did not like how I sounded when she rang me that week and emailed the manager at my GP practice, who telephoned my home the same evening.

The following morning, I received a further call from the surgery asking me about my illness and confirming that I was doing the right thing by remaining in bed. About an hour later I received a phone call from my younger son's social worker who said that he had heard I was ill and how could they (social services) help. I just cried and cried whilst explaining the situation I found myself in. Various services were then put in place to help us as a family to cope whilst I was ill.

After two weeks of being bed-bound and semi-conscious I began to rally, getting stronger as each day passed. Three weeks on my son returned to work and I continued to receive calls from social services at least once a week until we agreed that I was almost back to my normal self - whatever that is!

However, I do know that help is only a phone call away. It is important that everyone knows that support is available, especially during extraordinary times such as the pandemic, *but you need to ask for it.*

I feel I lost two weeks of my life during my illness and it has made me realise just how quickly things can happen. When I was a lot better, I updated all the documentation that I was putting off, including my will!"

4. Learning points and recommendations

	Learning Points	Recommendations
	Welfare Calls	
3.1	<p>Carers in the under 50's café felt that the simple 'chat' element was of limited value and some felt they were being 'checked up' on. To be properly effective and fully appreciated, welfare calls could be followed-up by practical support where a carer identifies difficulties.</p> <p>However, carers at the over 50s café were appreciative of the 'chat' element of the welfare calls, feeling that regular chat calls would make them feel less isolated during a stressful time.</p>	<p>3.1.1 Carers are not a homogenous group and such support could be tailored more to suit requirements of recipients.</p> <p>3.1.2 Naming the calls in more positive terms would be welcome to some as 'welfare' is felt to have a negative overtone.</p>



Accessing healthcare services		
3.2	Where clinic appointments had to be cancelled due to lockdown measures, some carers have been left feeling isolated and alone in looking after their loved ones.	3.2.1 Providers should prioritise making direct contact with patients/their carers to rearrange appointments proactively now that the NHS is ‘opening for business’.
3.3	Direct contact and clear information from the GP surgery, on shielding for ‘very vulnerable’ and ‘vulnerable’ people, would be appreciated by their carers.	3.3.1 GP practices could improve their contact databases by a) checking with patients that they have up-to-date mobile phone numbers and/or email address information or b) noting patients who are unable/unwilling to use email or mobiles and must be telephoned or communicated with by letter. 3.3.2 Reliable contact routes could then be used to target and communicate with patients with particular vulnerabilities.
3.4	An integrated, family-centred approach such as shown in the carer’s story, is crucial to the health and wellbeing of carers and their loved ones.	3.4.1 Positive experiences that demonstrate the value should be shared and celebrated widely as best practice in our local health and care services.
Other themes		
3.5	Many carers do not have ‘back-up’ plans made for if or when they are ill themselves and unable to look after their loved ones.	3.5.1 Consider how to implement a communications campaign aimed at carers, to stress the importance of being prepared with back-up plans if the carer is ill. It might include a brochure on Rutland resources for carers such as the example in appendix 1, and encouragement of the use of a ‘grab sheet’ containing medical and personal details of their loved one such as in appendix 2.
3.6	Some carers feel that there is little support available for carers of under 5s in Rutland.	3.6.1 Identify what respite support is available for carers of under 5s in Rutland. Information then can be included in the carers brochure mentioned above.



3.7	Carers of the under 50's feel that their loved ones have got used to very restricted lives and it may be difficult to get them used to going out again.	3.7.1 A rapid and safe restart of support and respite activities should go ahead, where possible, to bring structure back into the lives of loved ones.
3.8	When appeals on Education, Health and Care Plan (EHCP) assessments and provision of care packages go to tribunal, carers in Rutland may face a barrister, which is considered to be intimidating.	3.8.1 Clear information on the appeal process for EHCPs and care plans should be provided for all families with these plans. This should include simple guidance on the pre-tribunal mediation process and the use of advocates. One carer specifically wanted to know why Rutland is one of very few local authorities to use barristers in this way.

5. What's next?

Healthwatch Rutland will offer further carers' café sessions in the Autumn to hear about carers' experiences of the easing of restrictions and the restart of services.

The learning points and recommendations will be highlighted to service providers to help inform their plans going forward.

Acknowledgements

Healthwatch Rutland would like to thank the carers who joined the conversation and shared their experiences. Thanks also are due to Age UK in Oakham and Rutland Rotaract Family Centre for collaborating with the carers cafes.

About Healthwatch Rutland

Healthwatch Rutland is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:



- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement.
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Rutland and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

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