



*Reaching Out*

**A REVIEW OF DIGITAL OPPORTUNITIES  
TO SUPPORT THE MENTAL HEALTH  
OF CARERS**

## Mobilise

Mobilise is a tech-for-good startup on a mission to provide every carer with personalised information, guidance and support as they navigate the challenges of their role.

We have grown out of Zinc, a mission-led business incubator, and are seeking partners to work with us as we build a community of carers determined to transform the experience for a next generation of carers.



## Carers Trust

This report has been put together in partnership with Carers Trust. Carers Trust is a major charity for, with and about carers. They work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. (Carers Trust 2019)

Working closely with local Network Partners, Carers Trust aims to support carers at home by facilitating replacement care, and in the community, offering support and advice as well as help to get time away.



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# Executive Summary

Carers provide invaluable support and help to their family, friends and loved ones. They rise to immense practical, technical and emotional challenges, often with little training, preparation or even warning.

Without the contribution of carers, many people with additional needs would be unable to manage. Ensuring carers receive the support they need is a vital part of enabling them to cope now and in the future.

The role of carer centres is to provide or signpost the support needed by carers. This short study interviewed 5 carer centres at length, employing the lens of two questions: "What works well?" and "What are the challenges?"

The report found carer centres are having exceptional impact in diverse and challenging contexts. Nevertheless, the carer centres interviewed were constantly looking for new ways to support their users, and to access carers who aren't currently receiving support. There is a clear consensus that more could be done using digital channels to provide online support.

This study identified that the most effective forms of support for carers were characterised by:

- building a **sense of community and belonging**
- providing access to **reliable and relevant information**
- **tailoring support**, responding to the specific needs of a particular situation
- the **voices of carers** being heard and acted on
- well-signposted and integrated **partnerships with other agencies**

While there was plenty of good practice to be celebrated, carer centres were mindful of their limited capacity in the face of growing need. There is therefore a clear digital opportunity to extend the reach of carer centres and provide support to a wider population. This should complement and enhance (rather than replace) existing approaches.

## Next Steps

Mobilise is seeking to join forces with organisations who share our mission to seize the digital opportunity to find new ways of supporting carers.

[www.mobiliseonline.co.uk](http://www.mobiliseonline.co.uk)

# National Context and Background

## Who is a carer?

The UK Government defines informal carers as “people who look after family members, friends, neighbours or others because of long-term physical or mental ill health and disability, or care needs related to old age. This does not include any activities as part of paid employment” (Department of Health, 2018)

There are approximately **eight million informal carers** in the UK - a 35% increase since 2001 (Demos, 2018). Carers UK estimates this figure will rise by another 40% by 2037 meaning that **1 in 3 of us will be a carer at some point in our lives.**

Many carers do not recognise themselves as, or are reluctant to call themselves carers. Some simply consider the support they give to a loved one as being just part of family life. Caring for somebody often carries a stigma, particularly for those with mental ill health, and substance addictions, which makes carers reluctant to ask for help. This can make it difficult to ensure they get the support they need.



## Impact of Caring

Carers experience considerably higher levels of both mental and physical ill health with **72% of those surveyed by Carers UK reporting poor mental health and 61% reporting physical health issues due to caring responsibilities.**

The State of Caring survey highlights that of particular concern to carers are financial struggles, with approximately 20% in debt due to their caring responsibilities, and a further 37% struggling financially. This financial impact increases the longer they continue in a caring role. (Carers UK, 2019)

## Young Carers

There is considerable evidence to say that young carers are more likely to suffer from anxiety, stress and depression. (Young Carers Review of the Research and Data, Scottish Government, 2017)

**Young carers are a third more likely to report feelings of anxiety or depression than their peers,** according to GP Patient Surveys.

## Working and Sandwich Carers

Growing numbers of carers, particularly women, now find themselves struggling with multiple generational caring responsibilities.

**72% of carers are aged between 35-54 and approximately 60% are women.** In addition to being more likely to assume a caring role, women statistically were found to be more likely to:

- experience anxiety and depression as a result of caring
- find maintaining employment more difficult
- experience financial struggles than male caregivers in the same age group. (ONS, 2019).

This 'sandwich' group may even find themselves with an additional layer of generational caring, the 'club sandwich' carers, as they care for older parents, children AND grandchildren. (Zeitlow, 2014). With pension age entitlement rising to 68 in the coming years, working and multi-generational caring will place increasing pressure on working carers, particularly women.

The numbers of male carers is however also growing making up c.40% of carers in the UK. Men often find it harder to ask for support or to acknowledge their carer role. (Carers Trust, 2014)

## Older Carers

According to the 2011 Census there are over 1.8 million carers aged 60 and over in England. This represents nearly 16% of the population within this age range. A 20% of the 60-64 age group are carers, compared with just 12.6% of the population overall. The number of carers who are aged 85 and over grew by 128% over the last ten years. (Carers UK, 2015)



## *Research Methodology*

This research aims to explore themes of good practice in carer centres across the UK, particularly in relation to promoting mental health and wellbeing.

Carer centres visited for the purposes of this research had committed and knowledgeable staff teams who were passionate about providing support for carers. A number of staff had worked in the sector for many years. They were extremely conversant with the unique demography of their localities and the diverse support needs of their client groups as a result.

The research involved five semi-structured interviews with carer centres, at carers centres across the UK – Edinburgh, Newcastle, Suffolk and York, and Hambleton and Richmondshire. We also conducted unstructured in-depth interviews with two family carers.

Data collected was comparatively analysed to identify common themes and issues, and to highlight differences – whether demographic and local, or practice based. There was further desktop research undertaken to collect data from other carer centre websites regarding the carer support they are currently offering. Within the constraints of this research project, the information garnered offers only a snapshot of the services carer centres are providing in the UK.

Written consents were obtained from all participants.

All the centres offered a wide range of support and advice for carers of all ages. It is not possible here to enumerate the complete range of the services each centre provides.

For information about the full range of support and advice offered, please refer to the links to each carer centre found at the end of this report.



# Key Themes

All the centres emphasised the toll of caring on the mental health of their service users, and the planning and delivery of their services reflected this. The centres offered a wide range of support groups, advice and help lines, training, counselling, activity breaks, sitting and befriending services, relaxation treatments and therapies.

Several key themes emerged highlighting good practice.



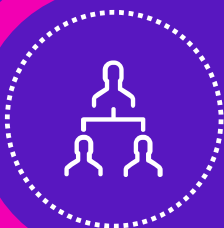
## Community

The most effective forms of support for carers, centred around a sense of community and belonging. With isolation a major factor in the mental health and wellbeing of carers, building community was consistently seen as a priority for the carers centre support offer.

There were different approaches to building community, including carer-led peer groups, befriending services or online forums.

## Personalisation

Where carers centres are most effective, they are able to provide tailored support which responds to the specific needs of a particular situation. Support needs to be person centred, adaptable to the particular needs of the individual, for it to be effective.



## Connected Services

One of the primary challenges for carer centres is one of identification – many carers don't immediately recognise their role, its implications and the need to be supported in it.

Where carers centres were connected closely with other support and health services, with clear patient and information pathways, carers were able to access support more quickly.

## Sharing good practice

Each carer centre recognised the benefit in sharing good practice, and was keen for more opportunities to share good practice through effective communication systems.

The new Knowledge Management Hub launched by Carers Trust in July 2019 should offer even greater opportunities for constructive and effective information sharing between centres.





# The Digital Opportunity



While there was plenty of good practice to be celebrated, carer centres were mindful of their limited capacity in the face of growing need. Consequently, they were keen to highlight where they saw opportunities for digital/online support to be effective as long as it was in addition to, and not considered as a replacement for other services.

## SPECIFIC GROUPS BENEFITTING FROM DIGITAL SUPPORT

Most services are currently delivered in-person, which enables a high-quality interaction with the carer, but limits the number and range of carers able to access the services.

### Young Carers, Young Adult Carers and/or Student Carers

These groups are less likely to identify as carers, and consequently less likely to access traditional services. Young carers transitioning from youth to adult services, or who are leaving home to go to college or university may need highly individualised support, particularly to help them move on from their caring role.

### Working Carers

Many working carers struggle to access carer centres due to time constraints, with working hours often clashing with centre opening hours. Carers' employers have highlighted the need for businesses to increase their support for employees who may be assuming care-giving roles outside the workplace, but this is not yet being met.

It was consistently highlighted that more work needs to be done to raise awareness amongst employers, colleges and universities to help them identify and support carers.





## Content suited for digital channels

Although not all support approaches can be offered online there were many examples raised of effective support that can be delivered digitally.



### Carers' Voices

The most effective form of support for carers creates an empathetic community. This is clearly best done in person, but digital support can be effective when sharing authentic stories of carers' experiences in an engaging and accessible manner. Blogs, podcasts, video diaries and other content can be highly effective channels.



### Information

Providing accurate, up-to-date information, expedient signposting and personalised support to navigate the complex and overly bureaucratic systems would be beneficial.



### Training

Online courses, like those offered by universities and other higher educational institutions or TED talks, webinars etc could significantly increase the accessibility of training in key issues for carers.



### Public Perception

Many carers experience substantial stigma and discrimination (particularly those caring for someone with a mental health – including dementia – or a substance misuse problem). Digital channels provide a particular opportunity to change public perception and raise the profile of carers.



## Effective approaches to digital support

For online content to be effective, the following themes were identified as key in the delivery of support.



### Personalisation

Where carer centres are most effective, they are able to provide tailored support which responds to the specific needs of a particular situation. The frustration of existing online support is that it can feel generic and inflexible.



### Aggregation

Current services online were often hard for carers to navigate with too much information over multiple sites and platforms. This could be confusing and sometimes counterproductive in terms of support and help to carers. Easy to steer, user friendly sites with links to condition specific and carer journey stages would be beneficial.



### Moderation and evaluation

Online support needs to be highly responsive, developing swiftly to user input and evaluation. Peer support groups (such as Facebook groups) are most effective when they are pro-actively moderated.





## *Case Study 1*

### York Carers Centre

York Carers Centre has a number of open access hubs which enable carers to drop in for peer support, information and/or advice. They also have wellbeing hubs to support carers own wellbeing.

York is seen as a wealthy city but it has pockets of deprivation. Using the last census, York Carers Centre has targeted, often hard to reach, areas of deprivation by setting up carer hubs, across different parts of the city.

Numbers of registered carers have been growing, with approximately 3.5k carers currently registered, supported by referrals from social services / the care sector. The majority of carers coming forward for support are 50+, and are evenly split male to female.

It is often harder to reach the 25-50 age group who are often working, and/or don't see themselves as carers. BAME carers can also be harder to reach, but those registered are reasonably representative of the York demographic.

Many of the carers registered at York Carer Centre are suffering from poor mental ill health as a result of their caring responsibilities.

## What's working well?

York Carers Centre has an advice line which runs each Wednesday evening, aimed at improving accessibility for working carers,

The Centre has a number of carers support workers who provide individualised emotional support, and who also undertake some Carers Assessments on behalf of the Local Authority.

*"Updating and keeping online services moving – who is funding and checking them?"*

## What are the difficulties?



The centre often struggles to recruit and maintain volunteers – many student volunteers in York go home after the summer



Facebook groups raise safeguarding/risk issues. Peer support groups often don't run themselves and a lack of capacity to effectively manage the groups is a concern.



Funding is often available to set up but not maintain online support initiatives, whereas in-person groups are usually funded on a longer term basis and so can develop over time.

## What are the opportunities to further support carers' mental health?



Opportunities and funding for online support groups to develop over time, particularly for those groups which prove to be harder to reach



There should be more shared online information and training about the stages of the caring journey with short blogs and podcasts / TED Talks



Specific get-togethers with carer centres, arranged through Carers Trust, to discuss carer mental health

*"Regarding funding of online services, it's in, out, and leave. They need time to develop and grow".*



# Case Study 2

## Hambleton and Richmondshire Carers Centre (Northallerton)

Hambleton and Richmond Carers Centre is one of three in the North Yorkshire locality. The centre currently has eight members of staff and has been running for 25 years.

The carer centre's approach is largely shaped by three demographic factors in the area:



Rural communities, making face-to-face engagement much more challenging.



**The presence of large military communities:** this leads to more young carers than would normally be expected, often supporting parents experience post-traumatic stress conditions



An increasingly elderly population, and the associated prevalence of age-related conditions such as dementia.

The Centre has developed a framework with support workers and referral partners to understand the local need.

There is now a 'Pathway' for carers which is person-centred and includes a risk assessment.

### Carer Support Levels

Red: Weekly 1:1 support sessions, plus acting as broker with external agencies

Amber: Monthly 1:1 support sessions

Green: Signposting to relevant group support



## What's working well?

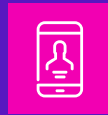
Partnership with other agencies: Given the large numbers of older carers supporting dementia patients, the Centre has an effective relationship with the local memory service, including joint team meetings, integrated pathways and automatic referrals. It is a very good example of successful early intervention. The Centre calls the carer within three days of getting the referral and they will meet with them in first month, supporting them with shock of diagnosis.

Facilitation: Light touch social groups (often themed to be condition-specific) seem to be very effective and accessible. Careful facilitation is crucial to enable those at different stages of their care journey to benefit. The groups are particularly effective for the 'middle' stages of caring.

## What are the difficulties?



Some rural areas in the locality are difficult to even access as a support worker – poor roads, lack of mobile phone signal, bad weather. It can be resource intensive, with some outlying areas taking all day to visit.



There are no online support groups, but it is a priority given the rurality of the area, provided there is sustainable funding. However, this also comes with issues like poor broadband and mobile phone coverage.

## What are the opportunities to further support carers' mental health?



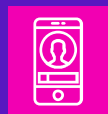
Online support for carers – the Centre would like to launch a website to help carers negotiate the complex array of support services and information and help signpost to different support organisations.



Utilising better digital communication to provide carers with online support, and to facilitate information and good practice sharing between and within localities.



Ensuring there is a Monday – Friday, 9-5 support worker who is on duty for online chat as well as phone or walk in.



Creating an online buddy system app, similar to Baby Buddy (NHS, 2018)





## Case Study 3

### Newcastle Carers Centre, Byker

There are an estimated 26,000 carers in Newcastle (Newcastle Carers, 2019). The Centre offers support to a very diverse demographic in Newcastle.

They have a budget for interpreters and strong working links with BAME services in the West End of the city. They support three main groups – young carers, young adult carers and adults.

#### What's working well?

A free counselling service is provided by volunteers who are currently training to become counsellors.

This is supported by a robust system of support for the volunteers through management and clinical supervision. There is an aim to have four to five counsellors working every week. The three-month waiting list is generally less than the waiting lists for similar services in the area.

There is an information line running from Mon-Fri. Texting and email works well for support for some hard to reach carer groups. Calls and emails from young carers can often come in at 2am.

## What are the difficulties?

There is a gap in preventative support – particularly in relation to family dynamics. ‘Grooming’ of the next sibling to become a carer when an older child moves on is something that the Centre often encounters. The impact on the mental health of young people cannot be underestimated.



The word carer can be problematic for some and also words which might be linked to the benefits system and local government – e.g. assessment. Terminology matters.



It can be important not to overload the carer with information in the early stages of care. The right level of information must be provided at the right stage for the person. Overwhelming the carer can be very counter-productive and upsetting

## What are the opportunities to further support carers' mental health?



There is a gap in support for ‘post carers’ – particularly those whose caring role has just recently come to an end.



The provision of digital information which focuses on the stages of the carer journey



Broadening links between carer centres to share good ideas and top tips online – accessible at support worker level



It can be very hard for some carers to leave the cared for person in order to access in person services. Online counselling may have its place as an additional offer of support.



Helping carers to realise that they have options and are able to make real choices.





# Case Study 4

## Edinburgh Young Carers

There are an estimated 29,000 young carers in Scotland - about 4% of Scottish children aged 4-15 years. (Scottish Government, Scotland's Carers Report, 2015)

Edinburgh Young Carers (EYC) is a specialist voluntary sector organisation. It offers support services and activities created to meet the needs of young carers - children and young people aged 5 to 20 years - who care for someone else in their home.

EYC groups carers into five groups according to age: 5-8, 9-12, 12-15 and 16-20.

EYC say the two biggest issues facing Edinburgh carers are the mental health of young carers (including a growing number of very young carers) and the lack of local authority provision for families and carers in the city. (Scottish Government, Young carers: Review of research and data, 2017)

*"We shouldn't be training young carers to be better carers, but helping them to move on."*

## What's working well?

The success of the counselling service (a trained counsellor and psychotherapist - offering an hour's support a week for up to 12 weeks,) through excellent feedback has resulted in an additional half day counselling being added this summer

The introduction of the Carer Scotland Act 2016 has made a big difference. Local authorities in Scotland now have a duty to have a carers' strategy. They have a duty to provide support. Every young carer is entitled to a young carer statement (the term assessment was changed as it was considered off putting) and older adult carers are now entitled to get a carer support plan (Carers (Scotland) Act 2016).

EYC checks that no young carer is doing inappropriate care and this is a very important part of their work. Support pitched at the right level for a particular age groups is paramount, but condition specific support can also be extremely beneficial

EYC tries to work with young carers for at least for six months after they cease their carer role, or in terms of their age, it looks for adult care support for them if their carer role is continuing. Carers transitioning from children to adult services, school leavers, young adults and students may all need carer support and post-care support.

*"Coming here gives me strength."*

## What are the difficulties?

There is a gap in preventative support – particularly in relation to family dynamics. 'Grooming' of the next sibling to become a carer when an older child moves on is something that the centre often encounters. The impact on the mental health of young people cannot be underestimated.



A wide range of young carers are struggling with poor mental health. Specific mental health support is extremely limited, with local waiting lists often extending to 18 months.



Young carers are not taken seriously by adults and adult professionals – for example when a parent of a young carer is admitted to hospital. NHS cards given out to identify as a young carer can make a difference.



Young carers experience particular pressure at the start of summer holidays, when their caring role increases.



Peer pressure and bullying on social media, particularly in the 12+ age group, have an emotional impact on young carers.



Some young carers self-harm and EYC has experienced the suicide of one of their young carers aged only 12.



## What are the opportunities to further support carers' mental health?



An increased focus on preventative early help for all young carers



Further work needs to be undertaken in identifying hidden young carers



There is a gap for 'post-care' support online – what is available after the caring role ceases or changes – for example a young carer leaving home to go to university or college.



"They need to be children first and foremost."



# Case Study 5

## Suffolk Family Carers Centre

Suffolk Carer Centre (SCC) has been going for over 30 years. Approximately 12k carers are actively registered. There are a higher number of female carers and a larger number of carers supporting someone with dementia and/or a mental health problem.

Suffolk has an ageing population. In 2039, 1 in 3 people will be 65+ in Suffolk (Healthy Suffolk, 2017) which is likely to continue to put pressure on local services.

*"Stress, anxiety, depression, isolation and alcohol/drug issues, are the main problems for carers."*







*"Stress, anxiety, depression, isolation and alcohol/drug issues, are the main problems for carers."*

## What's working well?

SCC works with schools and hospitals to introduce carer champions that run drop in sessions, give advice and talk at assemblies.

SCC offers youth mental health first aid, leadership for life training for young people and 'be your own best friend' – all geared towards putting themselves first. It is vital to recognise that people's lives are complex.

A closed Facebook group has been running for five years, to which you have to be invited to join. Administration of the group is very light touch, SCC doesn't remove comments, but they will put a message on and try to persuade people to take a particular discussion offline if need be. Advisors can use the group to share information about upcoming events.

A young adult carers' Facebook group was set up in 2012. Occasionally SCC has needed to actively moderate the group. As any member of the group is named, this has really helped to minimise safety risks and the potential for bullying

## What are the difficulties?



The centre is often supporting carers who are not in receipt of any other support services. SCC is often encountering carer problems first rather than GPs or social services.

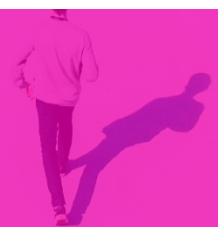


The growing number of couples where one older person (often with additional health needs themselves) is caring for their older partner, usually with dementia. These situations bring particular challenges.



Working age carers can be a particularly difficult group to reach. Those carers who have been forced to give up work due to their caring responsibilities can actually be easier to contact, whilst those still in work often remain hidden or difficult to connect with.

*"Asking carers about their well-being underpins everything that Suffolk do."*



## What are the opportunities to further support carers' mental health?

Online information can be a great resource – it must be seen as an additional resource however and not as an alternative for some in-person services. Social media can be a power for good if it used properly.

There is a significant proportion of young carers who do not know the basics of how to live well. We need to engage more with schools.

More needs to be done to support working carers – carer centres need to work with businesses to develop policies, create online training and awareness raising resources.

Increased links with other carer centres supporting people in the military services.

Continue co-produced work with CCGs and consider other co-produced research with carers and other organisations.



"Preventative work is crucial. It is time really, really well spent."

# Beth's Story

Beth is 47 years old and was born in Kingston upon Thames. She grew up in a close caring family with her mum, dad and brother.

She is married with two boys. Robert is the eldest, 17, and Christopher, 7.

Beth lost her dad to cancer when Robert was seven – he had been very close to his granddad. Beth took him for counselling, read him books and took him to a local hospice for music therapy to help support him. As a family they felt they gave him all the support that he needed.

Robert experienced bullying from an early age at school. Beth did what she could, but she was offered limited support by his school. Robert always had trouble concentrating at school and at 13 he became quite explosive, lashing out and hitting things.

Initially Beth and her husband tried to manage on their own but eventually realised that they were struggling to cope and spoke to their GP. Robert had an assessment. Although there was talk of him having ADHD, no formal diagnosis was made. Cognitive Behavioural Therapy seemed to be working, but he was discharged without warning, which Beth found very frustrating.



At the same time, Beth's younger son Christopher had been diagnosed with high functioning autism and hypo sensitivities.

Beth found the help she got when the boys were at pre-school fantastic, but as they have got older, she has had to fight for everything.

Recently, Robert has begun to self-harm. This has had a significant impact on Beth – she is frightened of even going into Robert's bedroom, scared about what she might find. Beth is relieved, however, that Robert is 'back in the system' and being re-assessed.

Beth has completed a number of courses provided by her local carer support centre, which were fantastic. She did a two-day course on mental health - "I found it fabulous". The courses gave her the equipment she needed to manage.

When Christopher was diagnosed Beth did an 'early bird' course on autism. Doing your best as a parent is very important to her. She is a parent first and carer second.

Although her husband is a great support and they are able to help each other, the demands on Beth are still immense.

Beth's physical and mental health has been impacted. She has experienced raised blood pressure and she often struggles with insomnia. Beth uses mindfulness techniques and yoga to help her cope and says she has an unhealthy relationship with chocolate which keeps her going!

*"It is utterly exhausting. I remember thinking -I can't do this anymore"*

But Beth has not had any specific help as a carer for her mental health.

*"I've not had a carer assessment, I didn't know about it until I had been on the course, it is now on my list of things to do. You always have to ask for everything. If I hadn't been on the course I would have been none the wiser. How can you ask for something that you don't know about!! I don't know the right questions to ask, about what is out there. I adapt and I make do"*

Beth and her husband want what's best for their sons and communication is really important. They are helping Robert to learn the skills to become more independent, but he still needs to learn a lot more emotionally in order to cope in the future. Beth constantly worries about them both and their futures.

Being with other people really helped. Sharing stories was so important and supportive, more important than she realised. Reading about information just wouldn't have the same impact on her despite describing herself as very old school and someone for whom pen and paper tick her boxes

*"Sharing stories was so important and supportive, more important than she realised."*

Beth doesn't have time to search through all the information available online - there is too much and it is often hard to navigate, but recognises it has an important role in supporting carers, particularly those who can't leave the person they support.

Beth knows about a subscription app for people with autistic spectrum difficulties called Brain in Hand, which she feels has the potential to be pivotal. The user can submit any question, or outline a dilemma they are facing, and they will then be guided through and supported to manage the situation.

"Gosh, that's where technology is amazing! To know that he has back up and support would really help. Everyone is different and needs bespoke support and care".





# Ruth the Survivor's Story

Ruth 'the Survivor' was born in Yorkshire, as a child cared for her grandfather who was gassed during WW1.

"I was born to be a carer"

"I went to see my sick Grandfather on my wedding day, because I knew he was dying"

Ruth trained first as a paediatric nurse and then later as a midwife. Her nursing role allowed her to use her early caring experiences to bring skill and empathy to her work and she won an award for her exceptional nursing.

Ruth and her husband had three children, one daughter and two sons. When her eldest son was only 20 years old, he was found dead in his room at university from an untreated infection. His death devastated the whole family. Ruth's other son and daughter were only 10 and 8 at the time. Ruth asked for counselling at this time, but her GP said that she and her family would get over it as they were strong.

Ruth believes the mental health difficulties her second son \*Tom has experienced throughout his life began after the tragic death of his brother, but she did not fully realise at that point the difficulties he was experiencing.

He appeared to be doing well as he grew up – he had his own business, a fancy car and a girlfriend. But when he was 22, he told his mum that he was taking drugs – his girlfriend had introduced him to cocaine – and he was now struggling with addiction.

This was the beginning of a 20 year journey for Ruth as she tried to help her son overcome his addiction to cocaine.

Ruth and her husband were terrified they were going to lose another son. They couldn't find any help.

Services designed to help people with mental health difficulties said it was a substance misuse problem and support services provided by organisations working with people with addictions said it was a mental health problem.

Ruth described how different it was trying to support her own son, even though in her professional life she knew what to do; when it was her own child, she felt adrift and helpless.

.....  
"You can't eat, you can't sleep, you're worried about making mistakes at work. I couldn't have him at home any more. He used to steal my car and my money. My husband didn't cope at all with this.

Sometimes I gave him money to buy drugs – and I felt guilty as if it was my fault. I felt like a failure because I couldn't cope"



Ruth was also looking after her own parents and parents-in-law at the same time as she was supporting her son. Within the space of four years her parents and in-laws all died. This was a desperately difficult time for Ruth.

Ruth did have some good friends though – ‘thank God’ – they gave her the moral support and a non-judgemental sounding board she needed. Help at this point came from them and not the professionals.

.....

*‘My GP was useless, useless, useless – on a scale of 1 to 10 he was minus 10 – in fact crap. I started taking sleeping tablets and anti-depressants to get me through’*

.....

But then there was a breakthrough. Two years ago, Tom began accessing services from a charity which supports people with substance misuse issues.

And it was here he met \*Sonja. Sonja had experienced similar problems with drug addiction in the past and she really seemed to understand what Ruth’s son was going through. Sonja told Tom that he deserved better and that she would help him. But told Tom not to bother lying to her because she knew the signs.

Sonja also vowed to help Ruth too. She didn’t shirk from telling them how difficult it was going to be, she pulled no punches, she levelled with them.

Ruth asked Sonja to let her help, so she and her husband could use the same strategies with their son. Ruth felt strongly that she also needed to protect her daughter and her husband.

*‘I will love that woman till the day I die. Tiny, dark haired and Celtic, she got through to my son’s soul’.*

Tom is 42 now and has been ‘clean’ for just over two years.

Sonja referred Ruth to her local carers’ centre. Ruth’s husband had just had a stroke, and Ruth was really struggling again.

*‘She told me to go to the carer centre and get some help. The support worker told me that they were there to support me, not my son. It was the first time I had ever been asked to think about myself’*



Ruth was invited to try a group session. She completed a five-week programme run by the carer centre. Ruth describes this carer run programme as life changing.

As Ruth's confidence grew and her carer centre had the opportunity to recognise the skills and experience Ruth had to offer, they asked her if she would be a carer representative on their interview panels. Ruth took part in a film, which won an award for the centre in 2019, and now she plans to become a trustee at the carers centre.

There were about 25 of us there – after the first session, it became apparent that it didn't matter what I did, how much I worried, how much money I spent on rehab, it wasn't MY problem. And I had to stop being a carer for my son, and to start caring for myself. For the first time in my life aged 70 I finally was able to think about myself.

When asked what advice she would give to other carers experiencing difficulties like hers she said:

"Go to your carer centre, in fact I would take you!"

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