

# How a Community Organisation Adapted During the COVID-19 Crisis

September 2020

By working with our colleagues in the Voluntary and Community sector, we have a series of reports on our website that capture the experiences and issues from the point of view of services and groups that support local people in the community.

This is an independent case study showing an example of one community organisation's story of adapting and what the future holds.

## About the organisation



Know Dementia, a local charity, is run by volunteers comprising family carers and qualified professionals who live and work with people with dementia.

## What were the immediate challenges?

Some of the practical challenges have included being able to *support* and *provide* for people who are already socially isolated due to dementia and protect both staff, volunteers and members. The enforced lockdown meant we had to stop all face-to-face meetings and support.

Their volunteers rang families regularly - to discuss health issues, refer on to appropriate services and so on. *They also provided different stimulations such as entertainment online and social media.* They used to have animals visit their cafes and this was provided online each Monday via Facebook, also singing entertainment on Fridays and Rosie's VE sessions on Tuesdays so there was something to watch and be used by families and carers as well.

The staff and volunteers have supported over 112 people and in West Sussex alone some 130+ hours per week of *talk time* to support families, which meant that their staff workload increased massively. *The calls are now more emotional and are longer and more complex as they have nowhere else to go.*

Some people do not have access to social media, so they contacted them by phone. They have been in contact with all members and families during lockdown. *They are trying to find different ways to do things; some members and volunteers from Sporting Moments speak weekly on Zoom and exercise and dance sessions are accessible through Facebook, email and the website.*

## How did members find the move to technology-based support?

The main impact on staff has been the change in roles - from café supporter to consultant via phone. Early on, the types of support members and families needed was for shopping and medications, but this moved to more emotional aspects.

“ Kate, who is 80 years, was concerned that the pharmacy changed her husband’s medications from blister packs. This meant that she could give her husband the wrong medications. The pharmacy informed ‘*they do not have time to make up blister packs.*’ ”

## How has COVID affected their finances?

The effect on their finances has been immense. *As an organisation they did not furlough any of their six staff, but they did reduce hours and pay by 20% as they wanted to continue to support their members, families and carers. This was not an easy decision to make but necessary financially.*

They do not receive any money from **West Sussex County Council** for their residents and have to fundraise to pay for three staff members and volunteers who support their West Sussex members. They do receive funding from East Sussex County Council. *This does mean an inequality between East and West in service funding.*

To have *their accounts audited costs OVER £1,000 a year so they are able to apply for funding - they have to find this money somehow.*

The main area of concern is not being able to fundraise.

They did apply for Rate Relief funds but were told they are not eligible as the rules do not apply to small charities, however they are trying the Lottery and TESCO have helped with £500 *which will enable them to buy PPE equipment ready to restart their community activities.*

## How have they begun to forward plan?

They have begun having conversations about going forward but are more concerned about ‘*creating a community*’. They used to have around 40 people attending (eight per table) but they do not yet know how they will manage social distancing - maybe by staggering attendance to ensure everyone is safe. *People are fearful of this and are scared to go out.*

## What are the concerns for the future, post-COVID?

There has been an increase in mental health and dementia as the effect on mental health of carers is not recognised and therefore no-one knows how this lockdown is affecting them. *Some of the phone calls are ok but the stories ‘break my heart.’* Stress levels are very high.

“ Joyce: I cannot put him into a care/nursing home now as he may get COVID. ”

*Access to social media is difficult, The Government has given children IT for homework and it would have been great if they could have also provided this for people living with dementia.*

*It is so important that the grant information is clearer, simple and a quicker process than it is now. They also need funding for day-to-day operations not just projects.*

## Contact details

To learn more about Know Dementia contact: [www.knowdementia.co.uk](http://www.knowdementia.co.uk)



*Supporting community action across Mid Sussex*

During this time of uncertainty, we have undertaken a range of different activities to support our members.

**General Enquiries:** 01444 258102

**Learn more from our website:** <http://www.msva.org.uk/>

**Admin Hub:** Delmon House, 36-38 Church Road, Burgess Hill, RH15 9AE

**Registered charity number:** 1158780

We have a simple ambition at Healthwatch West Sussex...  
to make local health and social care services better for  
people that use them.



We are here to listen, take action and influence positive change for local people living  
in West Sussex.

We record what people tell us and share this anonymously with those who make  
decisions about our health and care services.

**You can contact us in several ways:**



Telephone - 0300 012 0122



Email - [helpdesk@healthwatchwestsussex.co.uk](mailto:helpdesk@healthwatchwestsussex.co.uk)



Website - [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

You can also follow our social media channels to always be updated with the latest in health and social care news across West Sussex: [Facebook](#), [Twitter](#).

If you have questions about the content of this update, please either call 0300 012 0122 or email [cheryl.berry@healthwatchwestsussex.co.uk](mailto:cheryl.berry@healthwatchwestsussex.co.uk)