Community Partnerships

healthwatch West Sussex

How a Community Organisation Adapted During the COVID-19 Crisis

July 2020

By working with our colleagues in the Community and Voluntary 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
education, advice & support

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.

Our volunteers rang families regularly – to discuss health issues, refer on to appropriate services and so on. *We also provided different stimulations such as entertainment online and social media.* We used to have animal visits to our cafes, and were able to provide this online each Monday via Facebook, along with singing entertainment on Friday and Rosie's VE session on Tuesday, so there was something to watch and be used by families, and carers as well.

The staff and volunteers have supported over 112 people, in West Sussex alone, some 130+ hours per week of *talk time* to support families, which meant that our staff workload has increased massively. *The calls are now more emotional and are longer and more complex as they have no-where else to go.*

Some people do not have access to social media, we contacted them by telephone. We have been in contact with all members and families during the lockdown. *We are trying to find different ways to do things for 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 telephone. Early on the types of support members and families needed was for shopping and medications, but this has now 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*.'

Healthwatch Note: Some pharmacies are stopping the issue of Blister Packs, as they have been asked to prioritise their time. This is not a blanket "ban", but availability is being preserved for the most vulnerable who need them the most. This should be **after a robust assessment of your need by the community pharmacist**. It is the discretion of the community pharmacist to decide if they can support requests for blister packs, taking into account Equality Act 2010 requirements.

If you find yourself in the same position as Kate and are struggling, please have a discussion with the pharmacist so they fully understand your needs and can chat through some alternatives (that may even be more suitable) and reinstate the pack, if needed.

How has COVID affected their finances?

The effect on our finances has been immense. *As an organisation we did not furlough any of our 6 staff, but we did reduce hours and pay by 20%.* As we wanted to continue to support our members, families and carers. *This was not an easy decision to make but necessary financially.*

We do not receive any money from **West Sussex County Council** for their residents and have to fundraise to pay for 3 staff members and volunteers who support our West Sussex members. We do receive funding from East Sussex County Council. *This does mean an inequality between east and west in-service funding.*

To have *our accounts audited costs us OVER £1,000 per year so that we are able to apply for funding – we have to find this money somehow.*

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

They did apply for the 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 us to buy PPE equipment ready to restart the community activities.*

How have they begun to Forward Plan?

They have begun having conversations about going forward but are concerned more about 'creating a community'. We used to have around 40 people attending (8 per table) we do not yet know how we 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 concerns for individuals with dementia. There is also a concern around the mental health of carers which is not always 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.'* The 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 as the Government has given children IT for homework 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 currently. We also need funding for day to day operation not projects.*

Contact details

To learn more about Know Dementia contact:

www.knowdementia.co.uk

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