



**Tips and notes from the Webinar, 17<sup>th</sup> March 2020:**

**Gathering for people on direct payments, personal budgets and personal health budgets to share practical tips during COVID-19**

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## A. Guest Experiences



Miro Griffiths

Miro is happy to stay in contact with people by email. Miro has 24 hour assistance from a team of 7 personal assistants funded by the CCG via a personal health budget. Miro immediately looked at 4 areas of consideration

1. **Working in the house** > taking the guidance as best as can, taking a distance. Where personal care is needed we take considered measures, lots of hand washing
2. **Risk of exposure** > cleansing washing hands before they come in, change of clothing on arrival from outside clothes
3. **Contingency planning** > what happens if a PA goes off? For example a PA family had symptoms so Miro suspended their work with him and had considered conversations with other PA's to cover these shifts on the basis of time in lieu. Speaking to each PA asking for flexibility. If too many go off, do I have PA who can move into a "live in" situation for isolation for 7 days?
4. **Reliance on medical care** > If you develop symptoms I have discussed symptoms with my consultant. I have arranged to take PA's with me into hospital where possible

The other thing to consider is thinking about conversations with CCG taking advice

Professor Tom Solomon and deputy chief medical office there is now a clear demand for testing on staff.



Liz Wilson

Liz has a daughter and a brother with Down syndrome. She has been looking at her plans to revise them as part of her contingency plan. She started by a **top to toe jotter**. Using a body map to go through details that people other than me wouldn't know. Should I be ill this can be used as a contingency plan?

Top to toe jotter

- use a body map to help you list even little things you do
- you do things without thinking - what are they?
- ask all relevant people to add to the list

That can feel overwhelming to write everything down so this are **things that are absolutely essential**. I know these are not the aspirational plans these are for getting through a crisis

Starting the plan

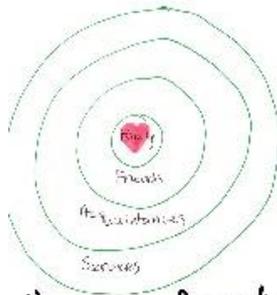
➤ using your jotter, divide support tasks into groups

Essential	Important	Can live without in a crisis
1.	2.	3.

- ↑ write detailed support plans + instructions for these first
- ↑ When you have the essentials covered, do these.
- ↑ Create detailed plans for this last. Don't feel guilty!

Next step was looking carefully at our circles of support and getting really specific on **what people can do and what we can give**. So as Liz is at home her daughter's PA is not needed so she is linking her to others who do need her support.

### Who can help?



Your circle of support

- ➔ list them
- ➔ ask for what you need
  - be specific
- ➔ make plan B with willing people
- ➔ offer what you can

Finally looking at one page profile, having emergency numbers laminated by the front door, top tips for what will help. **Email emergency plans out widely. Make a hospital bag** including all these

### Things that help

- ➔ One page profile - a great introduction and emergency guide
- ➔ list of emergency contact numbers - include who they are and how they can help
- ➔ list of alternative things to do, including favourite films, distracting treats etc.
- ➔ Share your emergency plans widely - only you know who needs them.

Liz is happy to be contacted, Facebook is the easiest route for Liz



## Will Case

Will has been an individual employer on a personal budget for 10 years and supports other disabled people. I have had conversations with my PA. **Have direct conversations** with your PA's on how you want to be supported. Making sure things are much cleaner than generally, what tactics to put in place if you or your staff gets the virus. We double wipe everything down and check on a daily basis. We are also looking at food we have for the week and extra not to stockpile but to have some reserved if I am not well. Ensuring **medications are at hand in case of emergency**, which I wouldn't usually have extra in the house. Updating all information for any back up PA's. Being calm and collective about it but **keeping an open approach**.

Will also happy to take any questions



## Karen Saville Croft

Karen is married to Gavin who has a personal health budget needing 24/7 support. We have a team of PA's to help manage. Karen started from the premise **Stay Calm, Stay Clean, Stay Safe**. Being practical, Gavin has been self-isolating for a long time, so it's more about people coming in and out of the house. In an ideal world we would still have people coming every day but now Karen is **requesting longer shifts to minimise the coming and going**. **Have emergency information, what you need, when you need it, have a bag packed. Mobilising of the troops** people who are well known who can pick up, family, friends and coronaheroes.

**Have an open meeting to talk about awkward questions. Maintain yourself in the best way you can with what you have**

## **B. Questions and responses live on the webinar**

### **Protective personal equipment?**

This has been requested that PA's are essential workers in the same way of social care and health staff. If you have an assigned contact in your CCG/Local authority write to them and let them know your intentions to use the budget on PPE. Knowing you might make instant decisions and be assertive and let the funder know your intentions and inform them by email "This is what we are doing do you have a problem with it". Do not do anything illegally with your budget. **Keep yourself safe**

### **Do PA's get statutory sick pay?**

Yes

### **What if PA's goes off sick?**

If you have local PA's in your area you can make a reserve list of PA that might cover.

### **If you ask a PA to self-isolate and they don't want to do?**

Could people use 111 & NHS for latest guidance for advice. Or would employment law be useful as to whether people could suspend. If a PA is showing symptoms you could suspend their work as they should be isolating or assign other jobs that isn't direct contact support?

### **How do we make contingency plans?**

Miro has an excel web sheet to know the flexibility and rota of PA's. Have a lead PA in your team to relieve some pressure. Use websites like PA pool. Contact CILs/DPO's and see if they have a network. Worse -case scenario there might be plans with life and limb services from the NHS & Social care before this use your community, use your neighbours. Do we have permissions to be flexible with your budget and can we raise this nationally so budgets are flexible to keep themselves safe. Will notes some people do have a contingency set up so make sure this is released and available. Clenton has a reserve of PA's and has a plan for using an agency, people might need to contact the council for this due to extra costs for an agency.

### **If there is a lock down do they need a letter for noting they are essential workers?**

Life and limb work and nationally classed as essential workers

### **Can we share the recording?**

Yes

### **What if we don't have family and friends?**

See contingency planning shared solutions

### **Specific question on ventilator cleaning?**

Karen noted it is cleaned in soap and water, wiping the mask as we use it. Increase general hygiene and keep washing hands keep clean. All basic advice, wash your hands, don't touch your face, use gloves etc.

## **Live questions and responses**

**Sandra >**

**Q** - I only have 1 PA at a time working so maybe my other could work with someone else, could we have a national agreement could they be paid to help for other people even though they are employed by me. Could we get councils to agree that if we share our PA's can they paid?

**R** - Can raise nationally and locally and could local providers facilitate this?

**Sarah >**

**Q** - Many of us are really low on Pa's due to low wage as ASC are not putting funds up front. For those who have very few PA's and are worried where do we go if they all go sick?

**R** - Worst case scenario – is there a life and limb service or is it really down to community? Look at local groups and neighbours.

**Gary >**

**Q** - Any help we can get from the CCG so thanks for looking into that. I have had to self-isolate we are just keeping one or two PA's. Can I pay myself and my wife from my PHB?

**R** - The guidance is families can be paid “where appropriate” in an emergency situation if people in the house need to be paid assert this and give the CCG or LA 24 hours to respond.

**Alison >**

**Q** - I have a 24 hour care package from when ILF went, I have a mixed package between LA, CCH and A2W > I don't have one person to go to any tips for negotiating? 2<sup>nd</sup> questions what guidelines are being made if we need to rely on the community, what safeguarding is available by the government?

**R** - Set out what you need to do and set out which ones you need and just email and inform people about what are you doing, its short term, its crisis driven. Don't go against statutory guidance. Inform people so there is a document trail of evidence of what you are doing and why? There is some safety guidance which is a major theme in the community groups. We are keeping it simple and behaving as good neighbours. For more cash exchange we have produced guidance that is pinned to the top of the coronaheroes Facebook page. There is a webinar from Covid19 mutual aid group which we can share. If we can get this to street level support this is a much safer way than having random helpers out of area. Coronaheroes are trying to work on a street level.

**We will update with information shared both formal and informal. So please share....**

**There is a formatted list of questions that we are working our way through and aim to theme as many as possible for our joint efforts of resolving.**

## C. Messages as a collective group

1. PA's working for people on Direct Payments MUST be classified as essential workers as part of health and social care workforce
2. Flexibility in how DP are utilised must be accepted and allowed without restrictive rules (including family payments)
3. Will a life and limb support service be available to people if all efforts of current provision of PA or agency support are exhausted? Especially those who do not have family and friends who are willing and able to step in?
4. If people end up relying on community public support will statutory services give support to the groups? Such as GP link, funding for employment advice, community funds for options.

## D. Contacts for help and support

### Guest contacts

Miro via email: Miro Griffiths [mirogriffiths@gmail.com](mailto:mirogriffiths@gmail.com)

Liz Wilson, Will Case & Karen Saville via Facebook or link by [admin@be-human.org.uk](mailto:admin@be-human.org.uk)

Julie via email: Julie Stansfield [Julie.stansfield@in-control.org.uk](mailto:Julie.stansfield@in-control.org.uk)

This community via [admin@be-human.org.uk](mailto:admin@be-human.org.uk)

General public and community via <https://www.facebook.com/groups/585056092098186/>

## E. Webinar themes

There are suggested future webinars on specific topics:

- (I) Contingency planning
- (II) Employment law
- (III) Emotional support

Please add more suggestions via [admin@in-control.org.uk](mailto:admin@in-control.org.uk) or [admin@be-human.org.uk](mailto:admin@be-human.org.uk)

## **F. Useful links**

All links and info will be collated on this page [www.be-human.org.uk](http://www.be-human.org.uk)

To join coronaheroes to give and seek in your local area use Facebook page <https://www.facebook.com/groups/585056092098186/>

**We will update with information shared both formal and informal. So please share....**