



Top Tips for Realising Person Centred Care through Volunteering

a project report by Volunteering Matters,
In Control and Ecorys

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Foreword

For anyone with a long term condition or disability, the boundary between health and life is blurred. Health affects every facet of a person's life, from their ability to work and be a hands-on parent, to their social life and the role they can play in their local community. For this reason, it is critical that our healthcare system and health professionals focus beyond medical conditions to consider a person's whole life. Healthcare, done right, should support a person's entire life not just their health.

Person-centred care is the route to making this possible and personal health budgets an important new tool in making person-centred care a reality for more people. Personal health budgets give people greater say in how they meet their identified health outcomes, allowing them to better integrate their healthcare into the other things that matter in their life. The NHS has made a commitment to increase access to personal health budgets for those who could benefit from them.

For some people getting a personal health budget is straightforward. But many people need help and support to think about how they want their care to be different, to navigate the different parts of the process and to manage their personal health budget once they have one.

Some of these roles need professionals and other paid staff but volunteers have a critical role to play too. Those who have a personal health budget can motivate others to take one up by sharing their story. Volunteers can support people to navigate the often confusing parts of the process, helping them to deal with the different professionals at each stage. Once someone has a personal health budget, volunteers can help them through the ups and downs and motivate them to keep going.

Volunteer support - both peer and community - has been a driving force behind personal health budgets and will need to continue if everyone who could benefit is to have a personal health budget.



Vidhya Alakeson

Chief Executive of the charitable trust, Power to Change

Introduction

This Top Tips guide is about how volunteering can promote and enable person centred care and support. It is about the introduction of personal health budgets (PHBs) and the important roles which volunteers and peer-supporters might play. The annex explains how the guide was commissioned and who was involved.

These tips are for **voluntary and community organisations** who are thinking about drawing on the skills, gifts and talents of volunteers to support people to get or manage a PHB. We hope they will also be useful for PHB holders themselves and for others involved in the process.



Always work with people: and always take their views seriously. Start with this.

- Understand volunteers' views and experiences; ask them what they know about personalisation, about PHBs and what they think is needed to support people using them. How can volunteers contribute and what do they need to make this work well?
- Track down and talk with PHB holders about their experience of getting and using their budget and how volunteers might help. If talking to PHB holders is not possible, then talk to people using personal budgets in social care.
- Also, talk to families and friends of PHB holders and others in local voluntary and community organisations.
- Build up a picture of what is needed and what is possible and check this out with people.



Plan your PHB volunteering activity. Think hard about what you are trying to achieve and what you need to achieve it in your locality and with the particular groups of people you support.

- Take time to define your volunteer offer: is it factual information about PHBs; telephone or face-to-face advice; is it short term, or on-going support and guidance. What exactly is the purpose and focus of the programme you propose?
- How and to what extent will you expect volunteers to get involved with the "technical" issues, particularly managing a PHB? Local organisations may already help people with book-keeping, staff recruitment, payroll and so on. Talk to them. They may focus currently on social care personal budgets with plans to extend into the new world of PHBs.
- Be as clear and succinct as possible when drafting your findings to help clarify your thinking. Share these with colleagues, discuss them and make a plan.
- Find out about PHBs in your locality. It's not the same everywhere. What does the Clinical Commissioning Group (CCG) say publically about PHBs? How many people have had one so far, and what health conditions will be offered a PHB? Make sure the CCG knows the range / type of support your organisation will be offering to PHB holders.
- Ask PHB holders about their experience of getting and using a budget. Do they have a better life as a result; how easy was the process; were they given clear information; and how straightforward are the arrangements for managing their PHB? How do these answers change what you and your volunteers will do?



What does your organisation need to support this work. What's the cost and how will you fund it?

- What support do *you* need as an organisation? Think about what you need to know and who do you need to talk to:
 - Appropriate people in the CCG and other health professionals depending on the health conditions you are interested in and on the local arrangements.
 - Your trustees and other key stakeholders. Explore what they can do to help and how it fits with other programmes and projects.
 - Seek out any local peer network of PHB holders or relevant user-led organisation. Find out their issues and how can they help.
- There may be other organisations supporting volunteers to do similar work either in your area or a neighbouring area. Talk to them and explore options for working jointly.
- Consider how you will resource the support to volunteers. Prepare an outline budget. This can be difficult and demanding work which needs to be fully supported – this has financial implications. Consider new funding bids or to talk with existing funders. Include volunteers' expenses in the budget; it is very important that volunteers are not out-of-pocket.



Consider the skills and information volunteers need to do the job.

- Volunteers need to be well-informed about PHBs:
 - who qualifies and in what circumstances
 - what PHBs can and cannot be used for
 - what is the role of the CCG and of other health professionals
 - what are the management options, how are they reviewed and what happens if anything goes wrong or someone raises a concern.
- Volunteers need to know the boundaries of their role, and where professional support should be sought. Tell volunteers who to go to if they or the person they are supporting need more information. Any or all of the following people may be able to help depending on the individual being supported and each particular circumstance:
 - the person's GP, specialist nurse, consultant, or someone else.
 - One or more people in each CCG will have special responsibilities for PHBs, for NHS Continuing Health Care and for long term conditions.
- Volunteers also need "soft skills" to engage with people in difficult circumstances, and to provide effective help and support. Volunteers involved in helping people make choices and develop their care plans will need to be trained.



Consider the best ways to find the best volunteers

- This work will not be suitable for all volunteers, so you need to decide how best to attract, inform and select suitable people. Most volunteer involving agencies have experience in doing this, but particular care is needed given the specialist knowledge and skills referred to above. Peer mentoring is particularly effective, bringing empathy and experience.
- If you are not experienced in recruiting volunteers, find out about best practice: the national volunteering charity Volunteering Matters (formerly known as CSV) can advise. See also the VODG (Voluntary Organisations Disability Group)/NCF (National Care Forum) volunteering toolkit – go to the VODG or NCF websites for more information. It is important that you develop a clear role specification; and a transparent and fair selection process.
- You also need to think about how many volunteers you want for this work. The number of people using PHBs is still small, though it is set to rise. It may be best to start small and work up gradually.
- Whilst some skills are common to all volunteers; the type, interests and experience of the volunteers you recruit may also be influenced by the nature of the health conditions that the personal budget holders have. Some organisations work with people with specific conditions – for example those with MS or another neurological condition, mental health issues or learning difficulties.



Think about the support volunteers will need in this work.

- In addition to their induction and orientation, volunteers need on-going support, supervision and training.
- It is especially important for volunteers that they know who to turn to if they need advice or information as someone's general circumstances (or their health condition) changes. There is information available on-line (see the section below), but different localities are implementing PHBs in different ways and volunteers need to know who to go to locally. Those supporting volunteers need to think through how they advise volunteers to deal with problems, who to turn to for advice and how they (the agency supporting the volunteer) gets involved.
- Volunteers need access to on-going support, supervision and training. This should be designed to:
 - pick up emerging worries and concerns
 - provide specific information and guidance on important issues, and perhaps most importantly
 - enable mutual exchange and support between volunteers themselves.



Decide what you want to say publically about volunteering and PHBs.

- Think about how you are going to tell the wider world about this work. How will potential and existing PHB holders, their families and health professionals know about your work?
- Consider information in different formats and languages. If you are working with particular health conditions, meet with local support groups or appropriate charities or campaigning organisations and send them written information. Consider people whose first language is not English and people from different cultures or faiths, to ensure these groups are not excluded from access to PHBs through unclear and inappropriate communication.
- Social media can help to get the message out, particularly via any local networks of volunteers or supporters you may have developed.
- In all communications:
 - think carefully about the words you use - it is easy to fall into the trap of using too much jargon
 - always be clear and use straightforward words and ordinary language that people can understand
 - always be respectful.



Remember that people crave a life, not a service. A PHB is a means to that end.

- This is particularly important and is very clear from the stories told by PHB holders. Never forget that people crave “a life not a service” and all PHB users will have a care plan which sets out what a good life means for them; a well-managed health condition is a means to that end.
- When someone lives with serious health issues, it is very easy to become drawn into thinking about their needs in terms of managing the condition. Doing this well is of course crucial and most people will spend their PHB in doing just this: purchasing equipment and support which they choose and which makes it easier to cope with their health condition.
- The role of a volunteer can be especially effective in supporting an individual to remember this – that there is a ‘life’ beyond ‘managing the condition’. Volunteers can help people to identify their own resources, those of their communities, and enable them to make best use of these beyond merely ‘a service’.



Don't make assumptions about the expertise of NHS colleagues. Remember that PHBs are still very new – many health professionals know little about them

- To date PHBs have been confined to people who qualify for NHS Continuing Health Care, a small group that most health professionals don't come across often, if at all. Some of the public debate has been misleading and has confused PHBs with other changes in the NHS.
- So, don't make assumptions that all health professionals know about, understand or indeed welcome PHBs. When you are talking with health professionals always be respectful, explain who you are, what you are doing and that your interest is to help individuals get a good life through more choice and control over their health care.



Remember you are not alone: there are lots of sources of help available.

- We list some of the important links and general resources below. But be prepared to do your own research, particularly if your interest is a particular health condition. And, again, and bear in mind that every locality is different, so you need to check how things work where you are.
- Most importantly, find out who can help in your area. This might be the PHB team in your local CCG. Or it may be a user led organisation or support group or even a particular individual or family member who has experience of using a PHB. There will be people with these experiences in neighbouring localities too and it may be worth casting your net wide.

Further information

Background, personal stories, guidance, news and official information about personal health budgets can be found on the NHS England personal health budgets website.

<http://www.personalhealthbudgets.england.nhs.uk/>

The organisation Peoplehub provides information about peer support for users of personal health budgets. **<http://www.peoplehub.org.uk/>**

In Control works across health and social care to advise people about personalisation and personal budgets. **<http://www.in-control.org.uk/>**

The Health Foundation is an independent charity, with a particular focus on the changes in the NHS leading to more person-centred care.

<http://www.health.org.uk/areas-of-work/topics/person-centred-care/>

The organisation Volunteering Matters (formerly known as CSV) promotes volunteering and social action across the UK and has projects in many localities.

<http://volunteeringmatters.org.uk/>

NCVO is a national membership organisation that champions the voluntary sector and volunteering. <https://www.ncvo.org.uk/>

NAVCA (the National Association of Voluntary and Community Action) is a charity that strengthens voluntary and community action. **<http://www.navca.org.uk/home>**

Vidhya Alakeson has written an introductory book, *Delivering Personal Health Budgets, a Guide to Policy and Practice*, published by Policy Press.

<http://www.policypress.co.uk/display.asp?ISB=9781447308522&>



Some personal stories

Andy Walker is a 37 year old man from Oldham. Nine years ago, at the age of 28 he was “living the dream” – ambitious, well-travelled, a successful businessman, planning his future...what could possibly go wrong? As he says, he soon found out: when on holiday in Goa, he dived into the sea, hit a rock and suffered a spinal cord injury which left him paralysed from the neck down.

Andy describes himself as a ‘fighter for independence’ and he is clearly someone with enormous mental resilience – but even for him the first couple of years following his accident were very tough. In fact he says he was extremely scared initially, scared that he wouldn’t be able to make a living, scared that he would somehow fail the people he cares about and most of all, scared that he would lose his identity and become simply a “disabled person” or simply a “wheelchair user.”

The system didn’t help: Andy describes a time when he felt he had no choice, no control, when his life was taken over by others who didn’t understand or particularly care about the person he is and the things he cares about. This phase reached its low-point when one day, one of the people paid to care for Andy -not someone he had selected to be in his life - robbed and abandoned him in a situation which could easily have had very serious, even fatal consequences.

Fortunately for Andy he survived, and perhaps even more good fortune - PHBs came along. In fact in ‘his’ case it wasn’t so much that his PHB “came along” – it was more that he made it come along, through years of intensive lobbying of his local Primary Care Trust (PCTs were the predecessors of today’s CCGs) and support of Local MP. Eventually, this made the difference. He now has control of his life again, he has a team of personal assistants who he has chosen and who he says have “become a seamless part of his daily business & family life.” Now he says he doesn’t start his day with problems, he starts it instead with opportunities to be grasped.

Now working as a motivational speaker and diversity consultant, Andy says he appreciates how difficult the introduction of PHBs can prove for many health professionals who are struggling with high workloads and limited budgets: fear of the new, the untested and unknown is always difficult. “But,” he says “think about how ‘You’ would feel, if you or indeed a loved one needed high levels of support to live life, who would you want to take the decisions, who would you want to be in control...?” And “surely,” he goes on to say “if health professionals really want to make a difference, to help make people’s lives better, then there really is no better way than through a PHB.”

In 2009, **Alex Mycawka** a former soldier who had always been in good health suffered an expected stroke.

Alex's health changed considerably overnight and he regularly suffered seizures that left him dependent on others for care and wellbeing. Alex was married at the time he became unwell and his wife became his main carer. Unfortunately this put a considerable strain on their marriage and eventually led to the couple's separation. Feeling incredibly low, Alex became depressed by his circumstances.

After his initial hospital care Alex returned home – he was offered rehabilitation but was only offered one session. He says that many of the people at the sessions were much older and at the age of 50 he still felt relatively young to have suffered a stroke. Many of the treatments being offered to him were very generic and didn't meet his specific needs.

Sadly, Alex became so depressed that he attempted to commit suicide and was referred to the mental health team, who introduced him to Personal Health Budgets. They suggested that he should join a pilot scheme operating near him. A number of people with different health conditions were trialling this new system whereby they would be given their own budget and would have responsibility for managing their specific health and care needs.

He says that the scheme was a lifeline as it allowed him to tailor his care to his circumstances. After suffering a stroke Alex was keen to improve his health and mobility but his application to a local gym had been turned down. Instead he used his budget to purchase a drum kit which allowed him to exercise his arms and legs.

Alex also uses his budget to employ a personal assistant who would help him on a daily basis to open his post, as well as making sure that he took the correct medication and ate properly. Alex had become incredibly frightened at the prospect of opening letters at the time he became ill and it was impacting on his health – knowing that he would have help with this made a significant difference to his wellbeing.

After his stroke Alex's short-term memory was also affected so he used his budget to purchase a SATNAV, which means that he no longer feels socially isolated. He used this new found freedom to also support other stroke survivors.

“ Being able to help other people has made a significant difference to my health. I feel a much more valuable person again. Having input into my care has also made a huge impact and has helped to improve my outlook

Now in a new relationship, Alex is determined to remain fit and well.

Some organisations' stories

Working with people with learning disabilities: the Volunteering Matters VOCAL project

VOCAL has been based in Norfolk for over 23 years. The project works with adults with learning disabilities, by providing well matched volunteers to support our beneficiaries to volunteer in their local community. This could be volunteering in a community centre or cafe, at a local allotment or environmental project, to name but a few.

We have been working with personal budgets for the past 3 years and have learnt that you have to enable your beneficiaries to understand the process and how they can use their budget to support the activities they wish to engage with.

People who volunteer with VOCAL say

“ with my current volunteering role I now have a sense of worth and purpose in his life that he just hasn't had' – **Service User**

“ CSV* has given both girls a purpose in life, and they have been given placements that are well within their capabilities, at places that they like, this gives the girls a great feeling of self worth. **Service User parent**

*The charity CSV is now known as Volunteering Matters

Working with people with Motor Neurone Disease: the MND Volunteering Fund Project

The project based in five areas across the East of England has been going for two years. It works with people living with or affected by MND and also provides support to health and social care professionals. It aims to empower people to take control of decisions about their care and help them make better choices.

Our volunteers; the 'Care Service Navigators'; work directly with people affected by MND, supporting them to navigate services to ensure their specialist and complex needs are met. By using technology more effectively, the project has created new ways of providing accessible information to people affected by MND. Our interactive web-based service directory brings together local services, and our secure confidential online forum enables healthcare professionals to share expertise and experiences. Professionals are further supported by the review and re-launch of specific information resources.

Our volunteers currently:

- Help people navigate and access health, social care and voluntary sector services.
- Increase awareness of PHBs.
- Support carers to recognise signs of breakdown and ensure they are supported to provide care for as long as they feel able.
- Provide a knowledge source for new commissioners and a link to hard to reach, vulnerable groups so they can meet their specialist needs and avoid crisis.

Each area does things differently and has varying knowledge of PHBs so we are working hard to:

- Find out the local deal and key decision makers.
- Support people with MND and Health and Social Care Professionals in understanding PHBs and the complexity of MND.
- Gather case studies in each area and evaluate how the CSN role differs in each area.

Families

- 'We are very thankful to you for your kind support and guidance during the course of events'
- 'You have clearly made things happen'

Professionals

- 'Found the CSN to be very knowledgeable and professional in my encounters with her'
- 'The team said that they had no qualms about involving the CSN at the MND professional forums at which issues were discussed'

Annex: this guide

This Top Tips guide is about how volunteering can promote person centred care and support. It is about the introduction of personal health budgets (PHBs) and the important roles which volunteers and peer-supporters might play.

The guide is the product of a project funded by the Health and Social Care Volunteering Fund and linked to the government's Integrated Personal Commissioning programme. The project was delivered jointly by Volunteering Matters and In Control.

Ecorys UK was the managing body appointed by the Department of Health to run the Health and Social Care Volunteering Fund between December 2009 and December 2014.

Volunteering Matters (formerly known as CSV) is a volunteering and social action charity: its **vision is of a society where everyone can participate to build strong and inclusive communities**. Volunteering Matters has many projects and programmes across the country which support volunteering in all its forms and from all sectors of society.

In Control is a national charity working to create **an inclusive society where everyone has the support they need to live a good life and make a valued contribution**. In Control pioneered **self-directed support** in adult social care and it also has programmes in children's services and health.

The guide draws on the collective experience and learning of Ecorys, Volunteering Matters and In Control from our work on this and on a number of related projects. More importantly it draws on the observations and comments made by PHB holders, family members, peer-supporters, volunteers, staff from voluntary and community organisations, professional staff and others who attended four workshops across England in winter, 2014/15. Ecorys, Volunteering Matters and In Control would like to take this opportunity to thank those people, without whose contribution this report would not have been possible.

The first part of this document provides some context. The body of the guide then presents a number of tips, which we hope will be of practical benefit.

The Integrated Personal Commissioning programme and personal health budgets

In announcing the IPC programme in July, 2014 Simon Stevens the Chief Executive of NHS England spoke of a need “to drive radical, people-powered commissioning of health and social care.” The aims of the programme are, he said:

- For people and their carers to have a better quality of life and achieve the outcomes that are important to them and their families.
- To prevent crises in people’s lives that lead to unplanned hospital and institutional care.
- Better integration and quality of care.

Today (early 2015), PHBs are available to those individuals who are assessed as having a need for *NHS Continuing Health Care*. NHS Continuing Health Care is a complete package of health and social care that is paid for by the NHS. Eligibility depends on four factors:

- the *nature* of the person’s needs, the impact on them and the types of care and support required
- the *complexity* of their needs and the skills required to care for the person
- the *intensity* (quantity and degree) of their needs and the support required
- the *unpredictability* of changes in their needs and the responses required

The government has stated that PHBs will also be available to other groups of people in the coming years, starting with people who have “long terms conditions,” conditions that cannot at present be cured but can be controlled by medication and other therapies; examples are diabetes, heart disease and chronic obstructive pulmonary disease. It’s not yet clear exactly which groups of conditions will be considered.

Personal budgets have been available to adults eligible for social care support for several years now, and part of the aim of the IPC programme is to bring the two types of budget together to make life simpler for individuals. The early work will pilot integrated health and social care budgets in eight demonstrator sites across England and for selected groups of people with relatively high levels of need.

The eight sites were announced in March 2015 and are Stockton on Tees, Barnsley, Cheshire West and Chester, Luton, Tower Hamlets, Hampshire, Portsmouth and a South west consortium. The selected groups are:

- people with long term conditions, including frail elderly people at risk of care home admission
- children with complex needs
- people with learning disabilities, and
- people with severe and enduring mental health problems.

This project

The aims of this project are to determine what now needs to be done to support volunteers to help with this process. We believe this will be best done through working with third sector organisations (and *volunteer involving agencies* in particular) to publicise and promote the benefits of person centred care and support, and to help these organisations and agencies develop a specific focus on the requirements of people who are using personal budgets.

It was agreed that the project would focus upon:

1. The rapidly increasing reach of PHBs, opportunities and threats for the third sector and for volunteer involving agencies in supporting people navigate through these processes.
2. The imperative to provide a more seamless experience for people, especially where budgets are accessed from multiple funding sources. This has been a particular issue of concern for people who have “lost” a personal budget when they have moved from social care to health care. A key question for us is how might third sector organisations help in this?
3. The need to promote the public understanding of personalisation in general and PHBs in particular; the role volunteers may play in this; and their needs for information and support.

It was agreed that we would go about this by meeting and talking with people across England. In winter 2014/15 four workshops events were held in four different regions of England.

The workshops

The four workshops were held in Cambridge, London, Preston and Leeds between December 2014 and February 2015. A wide range of people were invited, including:

- holders of PHBs and social care personal budgets,
- family members of the above,
- peer-supporters, people with direct experience of PHBs or social care personal budgets,
- volunteers,
- staff from user-led and/or voluntary and community organisations, particularly those offering support or brokerage to PHB or social care personal budget holders,
- staff from volunteer involving organisations,
- commissioners from clinical commissioning groups and local authorities,
- professional and/or clinical staff,
- others with a special interest.

The events were all well-attended, with 45-50 delegates at each event, almost 200 in total. There was some slight variation in the programme due to speaker availability across the four, but a common broad structure was used, as follows:

- Welcome, context and introduction to the project
- "My story" by a PHB holder (3 different stories over the 4 events)
- The Individual Personal Commissioning programme
- Table discussion: what we have heard, what is going on in our locality
- "Volunteers' contribution", lived experience from volunteers supporting people with personal budgets or PHBs
- Table discussion: do's and don'ts – a guide for volunteers and the sector
- Questions and answers
- Thanks and close

All of the events were characterised by lively debate, positive ideas and a real sense of excitement and enthusiasm. The presentations were of an extremely high standard and the project team would like to thank Alex Mycawka, Paula Fairweather and Andy Walker, PHB holders; and Pauline Matheson from MNDA and Yvonne Ogden and Helen Cooper from Volunteering Matters who described their experiences of volunteers' contribution.

A detailed record was made of all the discussions and is available on request from Emily Michelis at Volunteering Matters). For the purposes of this paper, these comments have been formulated into the Top Tips.



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