

## BOOK REVIEW

Helen Sanderson and Gill Bailey. (2014). *Personalisation and Dementia; A Guide for Person-Centred Practice*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-379-2

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### Introduction

At its heart, personalisation is about observing, listening and understanding what makes a person 'tick', that which gives them hope, enjoyment and meaning in their everyday life of tailoring and which enables the care and supporting patients either to help them to attain or *retain* these. Personalisation builds upon person-centred care, with an increased focus on choice and control for the individual. This book shows how adopting person-centred practices into everyday practice can achieve significant benefits for all people, regardless of their type or stage of dementia.

'Personalisation', then, is at the heart of what the Alzheimer's Society UK is working to achieve for people affected by dementia in terms of their everyday lives. Here, a 'one size fits all' service that you are expected to fit into is rejected, substituted by a genuinely responsive approach that delivers what people want, in the way they want it, by people they want to receive it from. It means more one-to-one conversation to establish how best to support someone and to keep having that conversation as desires and expectations change. The National Dementia Declaration of the UK has seven clauses: I have personal choice and control or influence over decisions about me. I know that services are designed around me and my needs. I have support that helps me live my life. I have the knowledge and know-how to get what I need. I live in an enabling and supportive environment where I feel valued and understood. I have a sense of belonging and of being a valued part of family, community and civic life. I know there is research going on, which delivers a better life for me now and hope for the future.

### Thesis

There is concern and speculation in the press about the quality of services provided in residential care home settings and the sustainability of the sector in these economically austere times. There is enormous pressure to

ensure the provision of quality care that is safe and dignified, but also efficient and responsive to the shrinking budgets of local authority commissioners. Add to this complex scenario the UK Government's vision for personalised services and it can be hard to understand what to focus on. Personalisation is the single biggest policy issue in social care and this book attempted to help professionals how to move on a day-to-day basis through person-centred practices. A combination of energy, commitment and active involvement from the organisation's leaders is needed. This does not necessarily require a big investment of money, just some additional training and support, to make a significant change for people living with dementia. The aim is to take an honest look at all aspects of the organisation, from where it is now, in order to understand what needs to change in order to make care more person-centred and able to deliver personalisation. This 'big picture' gives providers a basis from which they can then work out their priorities.

To deliver personalised services, we need to know what is important to a person, how best to support them, how they communicate and make decisions and how we are doing in delivering personalised services - what is working and what is not working. Person-centred practices have a strong role to play in helping people to be heard, finding solutions and changing people's lives, while also changing the culture of the organisations that provide care and support services. They include simple, effective and evidence-based practices - including person-centred thinking, person-centred reviews, person-centred planning and support planning. Person-centered thinking refers to a range of practical tools and skills that staff can use on a day-to-day basis to deliver more personalised services. Person-centred thinking tools enable staff to deliver personalised services by helping to answer the following questions: How does the person want to live and be supported? How can the person have more choice and control in his life? What is our role in delivering what is important to the person and how he wants to be supported? How are we doing in supporting the person in the way he wants to live? How can we work together to keep what is

working and change what is not working? How can we keep learning about the person and what we need to do to provide the best support?

Knowing the person requires a knowledge of what is important *to* and *for* a person. This, surely, is the first and fundamental person-centred thinking skill - the ability to learn what is important to someone, what is important for him / her and the balance between the two. Learning what is *important to* and what is *important for* is essential to help find the essential balance. Everyone finds that what is important *to* them and what is important *for* them are in conflict from time to time. Every way that we support someone with dementia has to take into account what is important to the person now within the context of the deprivation of liberty safeguards. Examples of what a balance between important to and important for looks like for people who are living with dementia include the many factors that this book considers, including an understanding of individual needs. For example: "Frank wants to go out every day, by himself. It is important for Frank to be safe from the traffic on the busy road. The balance between what is important to and for Frank is he wants to be able to go into the grounds of the care home every day, when he chooses, but the gates remain closed so that he is not able to get to the main road. It is important to Audrey to eat only bananas and nothing else. It is important for her to eat a balanced diet." The staff supporting Audrey have achieved the balance by giving food supplement drinks.

## Organisation

The person-centred practices outlined in this book show how to deliver genuine personalisation, where what is important *for* the person is balanced with what is important *to* the person's wellbeing. It is about the pre-requisites that make a life worth living: each person is an individual with his/her own needs, wishes and dreams to be recognised and met. This book shares the lives and journeys of people and their families. There are stories from people who have early-onset dementia and who live at home with support and from their families. The aim of the book is to look at the big picture and use the self-assessment tools to see how services are delivering personalisation. Proposals are more about changing routines or introducing one-page profiles and person-centred reviews for everyone (in care homes and domiciliary support). It is necessary to examine all aspects of the organisation, from where it is now, so what needs to change in order to make it more person-centred and able to deliver personalisation. In order to look at the big picture it is helpful to check progress in delivering personalised support for people living with dementia in care homes through a series of simple, practical self-assessments for providers who want to ensure they are delivering personalised services.

## Tools

Personalisation starts with the individual person: knowing who they are, what matters to them and how they want to be supported. A one-page profile therefore is the foundation of personalisation. Without this information, people are destined to be understood as a clinical condition - and their dementia as an organic disease will always be seen first. A one-page profile describes what people value about someone, what is individual about them, what is important to them and then how best to support them. It reflects the balance between what is important to the person and how we can ensure people with dementia stay as healthy, safe and well as possible.

Each one-page profile has a current photograph of the individual person. There is a bullet list of what really matters to the person from their personal perspective (even if others do not agree). It is detailed and specific. This section needs to have enough detail so that someone who does not know the person can understand who they are. It is not a list of likes and dislikes, but it reflects what and who is most important to the person. The detail is crucial. It should not be a list of two-word bullet points like 'having fun', but should instead provide a detailed explanation of what that means to the person - for example: '(Name) enjoys harmless practical jokes and time to sit and relax with people over lunch or coffee.' It should not include 'regularly' as this means different things to different people; instead, say specifically how often - daily? weekly? monthly? Rather than saying 'friends' or 'family', it is important to record people's names. It could include: who the important people are in the person's life and when and how they spend time together important interests and hobbies and when, where and how often these take place. Possessions that are important to the person, information about the rhythm and pace of life and any important routines remain vital perspectives.

The one-page profiles enable people caring for an individual to identify and appreciate their qualities and preferences. This particular section of the book summarises the person's positive characteristics, qualities and talents. It is not a list of accomplishments or awards, but it reflects what others value and appreciate about the person. It needs to have strong positive statements and not overly used words such as 'usually' or 'sometimes'. Suggestions can be provided on how best to support the person with dementia by a bullet list and what people need to know or do. It is not a list of general hints, but it is specific enough to enable anyone to support the person and know the most important things to do. It can include both what is helpful and what is not. Like the other tools, detail is important, so that people know exactly what good support looks like.

Routines are a way to ease ourselves through the day. Establishing details on someone's routines is an effective way to learn about what matters to the person and how thus to support the person's needs. The authors provide some routines of everyday relevance: morning routines such as waking up, washing and breakfast. Asking about evening routines includes getting ready for bed. Routines for

comfort enquire about what the person does when they have had a bad day and how they try and cheer up at these times. Routines for celebration include: enquiring about favourite ways to celebrate and how to react after a particularly good day. It is also helpful to identify what the person does to celebrate good news or achievements. Suggestions are provided for staff in residential care in conducting reviews by sharing information decided with the person present. The aim is to create a comfortable atmosphere that gives everyone an equal opportunity to have their say and for this information to be recorded. Information is recorded about the following questions: What do we appreciate about the person? What is important to the person now? What is important to the person for the future? What does the person need to stay healthy and safe and to be supported well? What questions do we need to answer? And what is working and not working from different perspectives?

To ensure that people with dementia have as much choice and control in their lives as possible and to deliver personalised services, we need to keep learning about what is important to and for the person and the balance between the two. Person-centred thinking tools help us learn about the person living with dementia and how they communicate and they enable us to capture this information on a one-page profile and through the use of communication and decision-making tools. Person-centred reviews are a way to keep this information updated and make sure it is acted upon by asking what is working and not working from different perspectives. Chapter 7 describes two more person-centred thinking tools that help us reflect and learn and add to the depth of information that we have about an individual and their life.

Using recommended questions reinforces a positive habit - that of valuing mindful observation and learning. This tool supports reflection and learning about what works and doesn't work. It can be used around a particular area of an individual's life - for example, sleeping patterns - or with a staff team around a project. They ask the following questions: What have you tried? What have you learned? What are you pleased about? What are you concerned about? The answers to these questions are based on what we know, what should we do next? The information gained through this process generates further actions and elicits information that can be used to update the individual's one-page profile. These tools are an efficient way to gather what people have tried and learned and to share this and make it visible to everyone. One approach is to put up flipchart pages in a team meeting, with the four questions (What have you tried? What have you learned? What are you pleased about? What are you concerned about?) and ask people to write on them. This is a way to ensure that everyone's perspective is heard and to make sure that issues are addressed and not overlooked.

In residential care the staff and managers have, in general terms, knowledge, skills and understanding of person-centred practices. Staff can be supported individually to develop their skills in using person-centred practices, so that the team has a clear purpose and *modus operandi*. They have an agreed way of working that reflects their values. They know what is important to each

other and how to support each other, what is expected of them, they feel that their opinions matter. Recruitment and selection are person-centred. Staff are carefully matched to people with sensitive attention paid to managing rotas. They have a positive, enabling approach to risk, training and development. Staff appraisals and individual development plans and meetings are positive and productive.

One tool provides a way to get a baseline of the current position, in order to make decisions about where to start to develop services further and to deliver personalisation. Through using this tool care staff can decide where to invest to make a difference. Staff can then take a detailed look at one area that you want to make more personalised. Having tackled one aspect of caring staff can then move on to another and by tackling it in bite-size chunks the transformation challenge will feel more manageable. Another option for developing services to become more personalised is to introduce person-centred reviews and one-page profiles for each individual. If reviews are person-centred this automatically makes it a straightforward way for a provider to find out what they are doing right and how they can improve.

## Conclusion

Personalising services for people with dementia and enabling people to have as much choice and control in their lives as possible, builds on person-centred care approaches and also requires carers to think differently about dementia. Care providers can explore the dementia journey and learn how to change and develop care practices to focus continually on the importance of relationships, active citizenship and community membership. The approaches clearly laid out in this book, if followed, will help ensure the drive towards personal budgets takes place within the context of delivering improved and tailored outcomes for individuals. The very practical tools in this book for: self-assessment, policies, knowledge and skills, healthcare providers can develop person-centred practice. The usefulness of this guide is that there are many instruments which can be photocopied for use in direct care practice, including one-page profiles of individuals. In using these instruments staff will enjoy getting to know the individuals whom they are caring for, enhancing relationships and work satisfaction in a personalised care environment.

## Conflicts of Interest

The author declares no conflicts of interest.