

MAKING IT REAL for carers

MAY 2013



Contents

Introduction	1
Information and advice: having the information I need, when I need it	3
Active and supportive communities: keeping friends, family and place	7
Flexible and integrated care and support: my support, my own way	10
Workforce: my support staff	13
Risk enablement: feeling in control and safe	16
Personal budgets and self-funding: my money	18
Using this guide to make personalisation real for carers in your local area	22
Acknowledgements	22
Further information and resources on carers and personalisation	23

Introduction

Traditional service-led approaches to meeting needs in social care has meant that carers have not always received the right help for the right issues in the right way, and at the right time. Personalisation in adult social care seeks to remedy this. The draft *Care and Support Bill*¹ aims to make provision to ensure that carers have maximum control over how their needs are met. This is done through a whole family approach to assessment and support planning, and the right to request a direct payment. Carers are, for the first time, recognised in law in the same way as those they care for. A guiding principle of the Government's approach to designing a reformed care and support system is that *'Carers are recognised for their contribution to society, as vital partners in care, and are supported to reach their full potential and lead the lives they want'*.²

Carers make an enormous contribution to our society and to the lives of the individuals they care for – whether they are family, friends or neighbours. However carers' needs, and the impact on carers of any changes made to the care and support system, can sometimes be overlooked. If personalisation and community-based support is to work well, it needs to work well for everyone, including carers.

*Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible: for example, that advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups, and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can be supported.*³

About Making it Real

Think Local Act Personal (TLAP) launched *Making it Real: Marking progress towards personalised, community-based support*⁴ on 17 May 2012. This resource aims to help organisations move towards more personalised and community-based support by providing them with practical steps to make personalisation a reality.

1 Draft Care and Support Bill Cm 8386 (2012)

2 HM Government (2012) *Caring for our Future: Reforming Care and Support*. White Paper, London: The Stationery Office

3 Department of Health (2010) *Recognised, valued and supported: next steps for the Carers Strategy*, London: The Stationery Office.

4 More information on Making it Real is available at: www.thinklocalactpersonal.org.uk/mir

The *Making it Real* programme was developed and co-produced with members of TLAP's National Co-Production Advisory Group, which is made up of people with experience of using services and carers from across the country. The resource consists of a series of 'I' statements, which describe what people might say if personalisation was working well for them.

Making it Real is divided into six themes:

- **Information and advice:** having the information I need, when I need it
- **Active and supportive communities:** keeping friends, family and place
- **Flexible and integrated support:** my support, my own way
- **Workforce:** my support staff
- **Risk enablement:** feeling in control and safe
- **Personal Budgets and self funding:** my money.

Each theme is supported by 'in practice' statements, which are examples of good practice or service features that show an organisation is making good progress towards personalisation.

About this document

Making it Real for Carers explores further what each theme means to carers and what this might look like in practice. It has been co-produced with carers and their organisations through a series of workshops held in Lewisham, Durham and East Sussex. The issues raised, approaches suggested and words used come directly from carers, and are presented in the six themes listed above. However, carers emphasised again and again the importance and need for a whole family, whole system, joined up approach. This is summed up in the words of one carer:

People need to understand that all of these are important to me as a carer:

- *The support I have*
- *My identity as a carer*
- *The person I care for*
- *The support around me.*

Information and advice: having the information I need, when I need it

Carers want clear, consistent, coordinated information that is easy to access, and information giving to be a two-way process, where their voice is heard.

If I am going to be in control as a carer, I need information about the choices available to me

– Carer

What carers want to see in practice:

- ◆ Information that is easily available so I don't have to fight for it
- ◆ Information that is easy to understand
- ◆ Face-to-face contact to sort out problems, not answer-phones
- ◆ Emotional support and someone to share my concerns with – talking to another carer is really helpful, being able to share and know I am not alone
- ◆ Council and NHS staff who know the system 100 per cent
- ◆ A regular review that takes a whole family approach helps me to consider my needs as a carer and provides a good platform for information and advice
- ◆ An information directory and catalogue of services and support and a list of contacts for help
- ◆ People including and talking to me as a carer wherever possible
- ◆ Confidentiality is not used as a barrier to communication with me as a carer.



Practical example: An integrated approach to carer support (Richmond Carers Hub)⁵

London Borough of Richmond upon Thames and Richmond Shadow Clinical Commissioning Group (formerly NHS South West London, Richmond Borough Team) has jointly commissioned this new

⁵ www.richmond.gov.uk/carers_hub_service

Carers Hub. It will include a universal information and advice service, emotional support, financial and debt advice, short breaks and leisure programmes, training for carers and opportunities for carer engagement, carer awareness training for professionals and strategic leadership.

Practical example: Accessible online information (Durham County Council Information Guide)⁶

DIG is Durham County Council's online information guide. This database lists a range of services and providers and is available to anyone through the Durham County Council website. It includes a section specifically for carers, which lists details of emergency support, carers' breaks, the carers' card and more. The information is also available in local public areas such as post offices, leisure centres and cafes.

Practical example: Carers and confidentiality in mental health (Royal College of Psychiatrists)⁷

The issue of confidentiality and information sharing between mental health professionals and carers is a difficult and complex one to resolve. The Royal College of Psychiatrists has produced a leaflet about the confidentiality issues that arise between mental health professionals and the carers of adults with mental health problems, in particular those who provide on-going help and support, without payment, to a relative, partner or friend. The leaflet describes some of the issues and provides examples of good practice to help address them.

Holistic support and services to carers: Peer support, advice and information (Carers Lewisham)⁸

Funded mainly by Lewisham Council and Lewisham PCT with additional money from fundraising, donations and trusts, Carers Lewisham is a Network Partner of Carers Trust and provides a holistic range of services for carers aged eight and upwards in Lewisham. The following case study demonstrates the type of work it does.

⁶ www.durham.gov.uk/pages/personaliseCategories.aspx

⁷ www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx

⁸ www.carerslewisham.org.uk



Zena is a parent of two boys: Billy (7 years) and Zane (4 years). Billy has a diagnosis of Autism (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) and Zena is sure her younger son has similar problems but has not been able to get him assessed. She is a lone parent and works full time.

Her employers are not very carer aware and things got very difficult when she had to take time off to sort out Billy's behaviour problems at school and his exclusions. She was very depressed and tearful, on the verge of a total breakdown.

Zena came along to some Parent Carers Sessions and other events at Carers Lewisham, where she met other parents and swapped experiences and information. This helped her to prioritise her needs and untangle 'the complete mess that is my life'. Carers Lewisham supported Zena to attend meetings at Billy's school, and helped her to devise strategies with the school to enable him to stay in mainstream education rather than unsettle him. Carers Lewisham also supported Zena in requesting an assessment for the younger child, who was going to go to the same school. He was diagnosed with ASD and some extra support was put in place. Zena was supported with tackling employment rights and benefits advice, completing forms and applying for grants. She has managed to keep her job and is considering going into further education. She is now in touch with lots of other organisations and has resources to draw on. She can see 'a bit of normality and a future for my life'.



Holistic support and services to carers: Supporting carers: an action guide for GPs and their teams⁹

This guide is produced by Carers Trust and the Royal College of General Practitioners and is aimed at helping GPs and their teams understand who carers are, why they need help, how they can involve them in patient care and how their practice can give them the support they need and deserve. It also demonstrates why providing that support is to the advantage of the practice team.



Holistic support and services to carers: GP surgery pack (The Children's Society Include Project)¹⁰

A pack was circulated to GP surgery practice managers and partners in Hampshire to highlight the support needs of young carers. This was in response to requests from young carers for GP surgery notice boards to display up-to-date information about support and resources for them and their families. The pack includes:

- ◆ A poster to display in the waiting area, with space for details of the local project, agency or nominated person in the practice offering support to young carers
- ◆ A poster for use on a staff notice board
- ◆ A 'quick checklist' for supporting and signposting young carers
- ◆ A leaflet for healthcare professionals titled 'Supporting young carers and their families'
- ◆ Contact details for further information and training.

I quite often go in with my mother when she goes to the doctor but they still don't recognise the fact that I'm a young carer and still don't pay attention or give time to that matter.

– Young carer

⁹ www.rcgp.org.uk/revalidation-and-cpd/substance-misuse-and-associated-health/~/_media/Files/SMAH/Carers-Action-Guide-Second-edition.ashx

¹⁰ www.youngcarer.com/resources/professional-resources

Active and supportive communities: keeping friends, family and place

Carers want the space to be someone other than a carer and to engage in activities in their community.

I need support for my son's social life so I can have one too!

– Carer

What carers want to see in practice:

- ◆ The space to be someone other than a carer
- ◆ Time to pursue my own hobbies and interests without worrying about the cared for person. As carers we all have different things we want in our lives, for example:
 - *I would like a holiday*
 - *I would like time to join in activities and sessions at the local art group*
 - *I would like time to integrate with the theatre group (I founded) and go to meetings*
 - *I would just like to have some fun, something to help my well being rather than 'education'*
 - *I need more time to myself.*
- ◆ Time and support to manage my own health needs
- ◆ Good information about the opportunities available to me as a carer
- ◆ Flexible support – more evening and out of hours support:

If the person you support has a social activity outside 'normal hours' it shouldn't fall on family and me. I need a life.

– Carer

- ◆ Employers, community services, schools and colleges that understand carers' issues and listen to carers – including young carers.

Practical example: Carers prescription service (Crossroads Care Cambridgeshire)¹¹

Crossroads Care Cambridgeshire (CCC), a Network Partner of Carers Trust, offers a Carer Services Prescription through the 80 surgeries and 631,000 patients it works with. The aim of this service is to embed carer awareness within primary care by using familiar business practices – such as prescription services – to improve recognition and early support for carers.

When a person visits their GP and is identified as a carer, their details are logged onto the Carers Register and, if more support is required, they are issued with a free prescription. Their details are then passed to CCC (with their consent), who get in touch within 24 hours of receiving the referral to offer information, a carers assessment and a visit to discuss the most appropriate form of support needed, which could include a free short break. They also direct the carer to find out more about caring, their rights, free services or benefits they may be entitled to.

Practical example: Worcestershire Carers Pathway¹²

The Carers Pathway is a newly improved process that began in August 2012. It gives all carers access to support, advice and information at the time they ask for it. When a carer requests (or is referred for) a Carers Assessment, they have the opportunity to be directly referred to Carers Action Worcestershire (a voluntary carers organisation) for a Carers 'Wellcheck' before receiving their assessment. The Carers 'Wellcheck' is carried out over the telephone as soon as the referral/request for an assessment is made. It enables the carer to think about what is important to them at that moment in time and what resources/strengths/networks are available to support them. Most importantly, it gives every carer time to talk and receive the advice that they need. If there is still a need for a Carers Assessment, the carer referral will continue on the pathway to the social work team with the information that has already been gathered at the Wellcheck, thus reducing duplication.

Practical example: Supporting carers in the workforce (Skills for Care)¹³

Carers in your Workforce Matter was developed by Skills for Care in partnership with Employers for Carers. It aims to give practical advice to social care employers on how to attract, retain and

¹¹ www.crossroadscarecambridgeshire.org.uk/our-services/support-for-carers/carer-services-prescription/ and www.cambridgeshireandpeterboroughccg.nhs.uk/Local-services/carers-strategy.htm

¹² www.worcestershire.gov.uk/cms/carers-unit/carers-pathway-and-assessment.aspx

¹³ www.skillsforcare.org.uk/developing_skills/carers/carers_in_your_workforce_matter.aspx

develop carers in their workforce. The guidance is divided into ten practical sections that allow employers the opportunity to ask questions around the prevalence of the carers they employ. It acknowledges the important role that carers play within the organisation, sector and society as a whole and suggests ways that carers' skills can be retained and developed. It also provides an opportunity to evaluate the impact of any changes made for working carers and highlights further support for employers and carers. The guidance provides some real life examples to demonstrate principles that are already being successfully employed by organisations.

Practical example: Dementia Friendly Communities (community cafe in York)¹⁴

Dementia Forward is a small organisation commissioned by City of York Council to run a project that will enable local businesses and cafes to become more 'dementia friendly'. They are working with a community cafe in Haxby, a village in the north of York, where a number of customers had memory problems. The people who run the cafe have benefited from support to 'skill up' and improve the welcome they give to people with dementia and their carers. People who go to the cafe feel welcomed, better understood and supported. This has resulted in some specific initiatives to support carers, including a one-off dementia awareness course facilitated by volunteers.

Practical example: Building community support and connections (Fair Shares – North Cotswolds)¹⁵

Carers are encouraged to join Fair Shares Community Time Bank to access practical help with everyday tasks such as gardening, getting a lift, shopping and so on. Fair Shares is also keen to maintain and build this network to support carers if they are unable to leave the house. This access to a wider support network can help families build community connections and feel less isolated and less stressed. It can also help them to access leisure activities. For example:

Lucy is a single parent to a boy who has Downs Syndrome. Lucy was struggling to have the space she needed in her own life to flourish at work and socially. Through the project she got in touch with a local woman who is occasionally available to take Lucy's son out during the school holidays. This enabled Lucy to have some respite, meet up with friends and catch up on her own social life.

¹⁴ www.jrf.org.uk/publications/creating-dementia-friendly-york

¹⁵ www.fairshares.org.uk

Flexible integrated care and support: my support my own way

Carers want services that talk to each other and are coordinated.

If the system is chaotic it disables me and prevents me from deciding the kind of support I need and when, where and how to receive it.

– Carer

What carers want to see in practice:

- ◆ Support through the 'maze of care' and good information about processes and timescales
- ◆ Choice in how I receive support and flexible provision that supports diverse needs
- ◆ Someone to talk to who won't judge: *'I don't want to feel guilty for caring or not!'*
- ◆ Good communication between different agencies, organisations and officials so that information is shared and I don't have to tell my story over and over again
- ◆ Good communication between education and social care, and information about transition from children's to adult services
- ◆ Good communication and coordination across borough boundaries so that if I am a carer living out of borough I am not disadvantaged
- ◆ A named social worker/assessor
- ◆ Good planning of services and change management that is equitable and involves people who use services and carers so that we can see the benefits of our involvement
- ◆ Regular independent evaluation of services
- ◆ A 'champion' who will support the person and the family in all areas (for example in school, respite care needs, etc).



Practical example: Pooled budget arrangements for carers' breaks¹⁶

NHS Bristol and Bristol City Council set up a pooled budget arrangement to provide carers' breaks through an Integrated Carers Team. The team works across health and social care, adults and children's services and the voluntary sector. Carers who might not otherwise get access to a service can receive a one-off direct payment from the team to buy something that will support them in their caring role. So far the pilot project is helping services support more people, particularly carers of people with dementia, young carers, parents of disabled children and people looking after someone with complex health issues.

Connor contacted the integrated carers support service after hearing about it from his partner. Connor has been caring for Sharon, who is in a wheelchair with ME and arthritis, for the last nine years. He does all the cooking, driving and general household duties for her. Connor applied for a small grant for a laptop to enable him to be in more regular contact through Skype with family in the US. He said: 'I'm looking forward to purchasing my laptop so I can stay connected with family I can't afford to fly and see.'

The University of the West of England is evaluating the project, and they will report their findings in December 2013.



Practical example: Working in partnership to produce a strategy for carers (Durham County Council)¹⁷

Durham County Council has worked closely with Durham County Carers Support, a Network Partner of Carers Trust, over a 10-year period. They have worked in partnership on joint consultations, training and information sharing. For example, to produce the joint strategy for carers, they undertook an extensive consultation process that included:

- ◆ A county-wide strategy event for carers and the people who work with carers
- ◆ Several local carer sessions and meetings across the County
- ◆ A County Durham Local Involvement Network (LINK) session
- ◆ Articles in a range of Durham County Council and Carer Centre publications.

¹⁶ www.bristol.gov.uk/carers

¹⁷ www.durham.gov.uk/pages/Service.aspx?ServiceId=6169



* Practical example: Whole Family Pathway (The Children's Society Include Programme)¹⁸

The Whole Family Pathway is an online tool for all practitioners and agencies that have contact with young carers and their families. It aims to ensure that the same process is followed for every family in need of support, no matter how they first make contact with an agency. The Whole Family Pathway is a resource for all practitioners in every council across England.

* Practical example: Working together to support young carers and their families¹⁹

Children and young people who care have the same rights as all children and young people, and the professionals providing them with support and services should help them to pursue this outcome. They should be able to learn, achieve, develop friendships and enjoy positive, healthy childhoods just like other children. Care services should be delivered in ways that sustain families, avoid the need to take on inappropriate caring roles and prevent further inappropriate caring.

The Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) have published a template for a local joint Memorandum of Understanding (MoU) between the statutory directors of children's and adult social services. It aims to provide a firm basis for working together and in partnership with health and third sector partners to support young carers, and provides variations to reflect local circumstances.

¹⁸ www.youngcarer.com/resources/whole-family-pathway

¹⁹ www.adcs.org.uk/download/misc/working-together-to-support-young-carers-adcs-adass.pdf

Workforce: my support staff

Carers want care workers they can trust and who are appropriately skilled for the particular needs of the person they support. They also want access to a good range of support services.

I want friendly staff who smile at me; who understand my role as a carer and listen to me.

– Carer

What carers want to see in practice:

- ◆ People delivering care and support who are reliable, knowledgeable and trustworthy
- ◆ All professionals, including care coordinators, consultants and GPs, talking to the carer about the needs of the person they care for and respecting their expertise and knowledge as the carer
- ◆ The care worker who connects with the person being supported getting to know that person's likes, dislikes and personality traits
- ◆ The care worker giving care and support with respect and dignity so that the carer doesn't always have to be present
- ◆ The carer feeling able to report poor care without being afraid of the repercussions
- ◆ Getting the care and support that is paid for (e.g. travel time and time for personal calls is not taken out of allocated support time)
- ◆ Getting extra cover when the carer needs it (for example, when they are ill) and domiciliary care workers who are available in the evenings as well as during the day
- ◆ Knowing their options on where to find good staff
- ◆ Training that provides staff with a good understanding of how to work with different people and respond to specific needs. This should include training in personalisation and in specific conditions e.g. from the Huntington's Disease Association, MS Society, mental health specialists and expert carers.

Practical example: Raising awareness and understanding of carers (Carer Aware and Young Carer Aware)²⁰

Carer Aware is an online training resource that was developed for Dudley Metropolitan Borough Council and is now used in over 40 councils around the country. It aims to provide staff with the knowledge and understanding they need to identify and meet the needs of carers.

Young Carer Aware is a companion course to this and has been developed in collaboration with Surrey County Council and Surrey Young Carers. It provides a practical understanding of young carers and their needs, and directs young carers to sources of support that are available to help them enjoy a happy, fulfilling childhood.

Practical example: East Sussex Carers Charter²¹

The Carers Charter was developed by Care for the Carers, a Network Partner of Carers Trust. It has five guiding principles that define how GP services within East Sussex should work to identify and support carers.

The Charter recognises good practice and assists those who need to improve by using the charter as a guide to measure their performance.

The five guiding principles are:

- 1) Team members are supported to develop and maintain their knowledge, skills and experience to ensure the practice identifies and supports carers.
- 2) Recognising carers as partners in care, and ensuring that they have access to the services they need to support them in their caring role.
- 3) Helping carers have a life of their own alongside their caring role.
- 4) Ensuring that carers stay mentally and physically well and are treated with dignity.
- 5) Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

Participating GP practices are assessed by volunteer Carers Charter Assessors, who look at the information and evidence provided and then award the practice with a star rating 'charter mark' based on their performance.

²⁰ www.cylx.co.uk/products/index.html

²¹ www.cftc.org.uk and www.carershut.org/content/bilingual-respite-bangladeshi-carers



*** Practical example: Bilingual and culturally appropriate respite services (Crossroads Care Central North London (CNL))²²**

Crossroads Care CNL, a Network Partner of Carers Trust, works to provide appropriate support and breaks for carers of all backgrounds and cultures and to connect carers with other services and organisations.

For the last 10 years, Crossroads Care CNL has run the Bangladeshi Carers' Respite project to identify carers who are currently not receiving services. It aims to provide them with bilingual care support workers and connect them with social services. Originally the focus was on Bangladeshi carers, with respite provided by Bengali / Syhleti-speaking staff, but the scope has now widened to include all carers, with particular aims to make contact with the Somalian, Chinese and Irish communities.

The project has helped to develop a greater awareness of the needs of different communities in Camden and link them to appropriate support. Although the project has come to an end, this learning has been incorporated into mainstream practice. Choice of support continues through the use of personal budgets and direct payments, and carers from all communities can contact Crossroads Care CNL for advise on how to access flexible and culturally appropriate support.

²² <http://crossroadscarecnl.org>

Risk enablement: feeling in control and safe

Carers want to know there is help available if things go wrong and that they can access the support they need to get on with their lives without worrying.

Over the top risk assessments can get in the way of me having a life.

– Carer

What carers want to see in practice:

- ◆ Knowing there are support workers I can contact in an emergency
- ◆ Knowing there is a safety net to support me in my caring role
- ◆ Front line workers should use their common sense and get away from the mind-set that *'this is my job'*
- ◆ People who use services and carers who are listened to
- ◆ Health and council staff who communicate and share information on care needs
- ◆ Having access to training such as first aid, hygiene, moving and handling, etc
- ◆ A global review of my needs that considers all aspects of support, the options available to me, joins up services and takes a whole family approach
- ◆ Staff with good listening skills who sort out issues promptly so there is no breakdown in care
- ◆ Finding sensible ways of managing risks that don't stop me and my family having a life.



Practical example: Emergency support (East Sussex)²³

The Carers Emergency Alert Card is a scheme provided by Care for the Carers. Carers complete an emergency plan, providing information about family members, friends or neighbours who might be able to help the cared for person if the carer was involved in an

²³ www.cftc.org.uk and www.eastsussex.gov.uk/socialcare/carers/emergency/default.htm

accident or emergency. Carers are then issued with a card that they keep with them. The emergency services are aware of the card and use it to ensure that the cared for person has support in the event of an emergency.

East Sussex County Council (ESCC) provides a similar scheme called Carers Respite Emergency Support Service (CRESS). The principle is the same as the Carers Emergency Alert Card, but CRESS can also provide short-term replacement care. In the event of an emergency, if none of the named people are available, ESCC will provide care workers from their own care team for up to 48 hours (72 if it falls over a weekend) until the carer is able to continue caring or longer-term support can be arranged.

Practical example: Be Bothered! Making Education Count for Young Carers²⁴

Family Action's new *Be Bothered* campaign (Family Action 2012) aims to raise awareness of young carers in school. It also aims to work with schools, councils and Government to improve outcomes for some of the most vulnerable pupils and their families. As part of this campaign, young carers carry a credit card-sized ID card that has their name and photograph on the front and a list of specific allowances to their needs on the back. These allowances include the ability to have a mobile phone in school to contact parents, occasionally being able to hand in homework late, leniency towards late arrival, ability to leave early for caring needs and being given time out periods if required. It provides evidence that the organisation has recognised the individual needs and extra support required by that pupil.

Practical example: Carers Emergency Card Scheme (York Carers Centre)²⁵

The Carers Emergency Card Scheme is a partnership between York Carers Centre, a Network Partner of Carers Trust, and City of York Council's Warden Call Service. It helps carers set up an emergency plan for a sudden, unplanned and temporary situation where they are not able to give the care they usually provide and they are not able to make temporary arrangements themselves. The Carers Centre helps carers create and record their plans and the Warden Call Service provides 24-hour, seven days a week support in an emergency. Carers say that the scheme helps them feel more confident and gives them peace of mind when they are away from the person they care for. The scheme has successfully put plans into action to safeguard and support the person being cared for. The scheme has also led to an increase in registrations at the Carers Centre and has helped to create and strengthen links with other local services.

²⁴ www.family-action.org.uk

²⁵ www.yorkcarerscentre.co.uk/content/carers-emergency-card

Personal budgets and self-funding: my money

Carers want to be sure that the money available for support can be used in ways that work well for the person they care for and for the whole family. They want to make decisions about how this money is used. They want good value, safe and high quality support to be available.

I value my direct payments and understand how to use the money well. Support to use direct payments and help with finance and budgeting are really important to make it work!

– Carer

What carers want to see in practice:

- ◆ A carer's personal budget that can be spent on what's important to me
- ◆ The option to have maximum control of the money in my personal budget by receiving it as a direct payment
- ◆ Carers' allowances for all carers – regardless of their age. The caring role that older carers undertake should be recognised and respected, and young carers should also get a budget or allowance
- ◆ A good range of support services available locally including good quality appropriate respite, affordable and safe transport and a wide range of social activities
- ◆ Transport included in any activities for my cared for person
- ◆ Good information and the right support with direct payments
- ◆ Choice in how I receive support
- ◆ Continued direct payments when a person moves from social care funding to NHS personalised care.



Practical example: The Torbay Enabling Service (Crossroads Care South West (CCSW))²⁶

The Torbay Enabling Service is a flexible, personalised service run by CCSW, a Network Partner of Carers Trust. It aims to help carers and their families work out what support they need and find solutions to the issues that cause them the greatest stress in their caring role. Its flexible approach can be summarised by the question: '*What would a break mean to you?*' It has a particular remit to reach carers previously lacking any support or those not engaged with statutory support. It also aims to develop wider community capacity to help carers through developing informal networks of support. This helps to reduce carer isolation and dependence on traditional services.

The service helps carers to focus on their own needs and to look after themselves. It encompasses active listening, help with self-assessment, support and breaks planning, advocacy and where to get more help. It also aims to help carers tackle stress issues outside of the caring role. The service has an underlying ethos of enabling and empowering the carer, promoting self-help and community / voluntary support solutions.

If you had come and sorted these things out for me, it wouldn't have been as good as what you did for me. I went back and I sorted it out for myself.

– Carer



Practical example: Carers Support (Bexley)²⁷

Carers Support, a Network Partner of Carers Trust, supports carers who arrange personal budgets for the person they care for. It offers ongoing support around managing budgets, keeping accounts and employing care staff, and provides support for people who are self-funders. The scheme takes an individual approach to each case, offering differing levels of support to meet the needs of each particular carer or family – this could mean one-off support planning or providing ongoing help. It has also developed a checklist to help set up a carer as a new employer, covering issues such as insurance, paperwork, training and other human resources issues.

Often carers are not aware of their rights and what is available to them, so advice and information are a big part of this scheme. Having dedicated and well-informed staff and taking a personal approach to each carer or family have been particularly important to its success. Understanding the individual needs of the carer also means that the scheme can provide specially tailored levels of support.

²⁶ www.carers.org/local-service/south-west/services/enabling-service

²⁷ www.carerssupport.org

Practical example: Bristol Integrated Carers Team²⁸

The Integrated Carers Team helps adults and young people access budgets for benefits such as short breaks, taking up a hobby or buying specialist equipment for the home. These can be given as direct payments. For example:

Divya has four young children and provides palliative care for her father (she had previously done the same for her mother, who has now died). Her father received a direct payment, which he used to pay for a family member to come from India for a period of time to give his daughter a break from her caring role. Divya received a carers' direct payment, which she used for her children to attend summer play schemes to give herself some social activities after the family member returned home.

Practical example: Personalised support packages for BME dementia carers (The City Bridge Trust Dementia Project)

The City Bridge Trust Dementia Project, run by Crossroads Care Bexley, provides tailored support packages to people with dementia and their carers. It enables carers to have a break from their caring responsibilities, knowing that the person they care for will receive high quality care from trained staff. Support packages are also available to those people in the early stages of dementia that may or may not have a carer.

The project involves the delivery of awareness-raising presentations at community groups and events, including the Bangladeshi Women's Group and the Asian Ladies Group, where bi-lingual presentations were made with the help of translators. It also involves gathering the views of carers and communities to identify gaps in local services and barriers that individuals may face in accessing them.

There has been a lot of positive feedback from carers who have received support. When asked what difference the care support package makes, carers' comments include:

Great difference, time gives me a chance to clean and shop.

– Carer

As main carer, this gives me a day to myself.

– Carer

²⁸ www.bristol.gov.uk/press/health-and-adult-care/new-support-carers-already-helping-families



Practical example: What on earth are personal budgets? (Carers Trust training course)

What on earth are personal budgets? is an introductory course co-produced by carers for carers explaining the Personalisation Agenda. Ninety five per cent of carers who participated in the course would recommend it to other carers, and comments such as ‘*Opened my eyes to what you can achieve,*’ are typical from carer participants. Carers’ services and council carers’ leads also agree on its value. A YouTube video²⁹ has been produced to give more information, and an independent evaluation³⁰ reports the outcomes and learning from the early stages of the project.

As a result of *What On Earth are Personal Budgets*, carers’ centres have developed and delivered additional courses on other priorities identified by local carers, including managing personal budgets, confidence building and support planning. Contact Beryl Cross (bcross@carers.org) for more information.

A PERSONAL STORY: a care plan that works well for the whole family

Daniel is 39 and moved out of a small group home into his own house 15 years ago. He has learning disabilities and some associated health problems and needs considerable support.

Daniel has a personal budget. His detailed care plan is worked out with him and his family alongside his support workers and the local authority. It is reviewed annually.

Daniel’s support is focused on Monday-Friday, with his family providing support at weekends and over holiday periods. The support includes three days at a horticultural project. He has daily support during the week, and two full days with a support worker when he volunteers on a local ecology project. He has also been able to participate in a community arts project led by a local gallery.

He is anxious to be as independent as possible and uses telecare to cover nights and additional daytime security when needed. The additional support of telecare, together with reliable but flexible and creative weekday support has enabled his parents to work and to undertake other family responsibilities.

More video stories about how personalisation has improved outcomes for the whole family can be found on the *Making it Real* website.³¹ For carers stories, see in particular Jo’s story, Alan’s story and Philippa’s story.

29 www.youtube.com/watch?v=yMz7kusxxjY&feature=youtu.be

30 static.carers.org/files/personalisation-course-interim-evaluation-2012-2-1-6204.pdf

31 www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/videos

Using this guide to make personalisation real for carers in your local area

The statements in this guide can be used to find out what is happening locally for carers and to help carers identify what could be done better and how this can be achieved.

Actions focusing on improving services for carers and whole family approaches can be included in an action plan that organisations can put on the *Making it Real* website. Organisations that put their information on the website will see themselves as part of the *Making it Real* map. All organisations on the map can contact one another to check on each other's progress.

Anyone can check the progress of organisations in their area, comment on how they are doing and how they are including carers in their action plan. If your local council or carers' organisation is not already signed up to *Making it Real*, you can encourage them to do this and to work towards achieving a *Making it Real* Kitemark to show that they are a *Making it Real* organisation.

For information and tools to help you use this guide and develop your *Making it Real* project go to: www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/supportMaterials

Acknowledgements

Carers Trust, ADASS and TLAP are very grateful to the many carers and staff who contributed to this document. By providing knowledge, examples and information, they have helped to illustrate how personalisation can produce better outcomes for carers as well as the person they support.

Particular thanks go to Carers Lewisham, Durham and Chester le Street Carers Support and Care for the Carers East Sussex (all network partners of Carers Trust) for giving their time and knowledge at the workshops that helped to produce this guide.

Further information and resources on carers and personalisation

CARERS TRUST'S CARERS' HUB

Carers Trust's Carers' Hub (www.carershubs.org) resource is for anyone looking to commission and develop personalised services for carers. By showcasing a variety of original and innovative practice examples from across the UK, the site aims to inspire ideas about creative and inventive ways to deliver services in your area. The Hub is a model of comprehensive carer support and is based on the outcomes of the refreshed National Carers' Strategy for England (www.carershubs.org/content/outcomes-national-carers-strategy). It is an effective tool for mapping local services in consultation with carers, and feedback has been positive.

The Carers' Hub helped us to engage with carers and highlighted what they valued, not what we thought they should value.

– Commissioner

Carers Trust has been working with a number of local councils to co-produce a toolkit to outline a simple process for using the Carers' Hub model in consultation with carers (www.carershubs.org/content/toolkit-mapping-local-services-using-carers-hub). The toolkit is currently being piloted, and a final version will be available on the Carers' Hub website.

WEBSITES

Bangladeshi Carers' Respite: www.carershubs.org/content/bilingual-respite-bangladeshi-carers

Bristol Integrated Carers Team: www.bristol.gov.uk/press/health-and-adult-care/new-support-carers-already-helping-families

Care for the carers: www.cftc.org.uk

Carer Aware and Young Carer Aware courses: www.cylux.co.uk/products

Carers Emergency Alert Card: www.eastsussex.gov.uk/socialcare/carers/emergency/default.htm

Carers Lewisham: www.carerslewisham.org.uk

Carers Trust training course What on earth are personal budgets?:

www.youtube.com/watch?v=yMz7kusxxjY&feature=youtu.be

Carers Trust's Carers' Hub: www.carershub.org

Carers' case studies (Jo's story, Alan's story and Philippa's story):

www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/videos

Carers' Support (Bexley): www.carerssupport.org

Crossroads Care Bexley Dementia Project: www.crossroadscarebexley.org.uk/services/dementia

Crossroads Care Cambridgeshire's Carers prescription service:

www.crossroadscarecambridgeshire.org.uk/our-services/support-for-carers/carer-services-prescription

Crossroads Care Central & North London: www.crossroadscarecnl.org

Crossroads Care South West's Torbay Enabling Service: www.carers.org/local-service/south-west/services/enabling-service

Durham Information Guide: www.durham.gov.uk/DIG

Fair Shares Community Time Bank: www.fairshares.org.uk

Making it Real: www.thinklocalactpersonal.org.uk/mir

Richmond Carers Hub: www.richmond.gov.uk/carers_hub_service

Royal College of Psychiatrists' Carers and confidentiality in mental health:

www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx

The Children's Society's Include Project: www.youngcarer.com/resources/professional-resources

Think Local Act Personal (TLAP): www.thinklocalactpersonal.org.uk

TLAP's National Co-Production Advisory Group: www.thinklocalactpersonal.org.uk/Browse/Co-production/National_Co-production_Advisory_Group

www.thinklocalactpersonal.org.uk/Browse/Co-production/National_Co-production_Advisory_Group

Worcestershire Carers Pathway: www.worcestershire.gov.uk/cms/carers-unit/carers-pathway-and-assessment.aspx

York Carers Centre's Carers Emergency Card Scheme:

www.yorkcarerscentre.co.uk/content/carers-emergency-card

York Dementia Without Walls: www.jrf.org.uk/publications/creating-dementia-friendly-york

PUBLICATIONS

The Princess Royal Trust for Carers & Royal College of General Practitioners (2011) **Supporting carers: an action guide for GPs and their teams**, London, RCGP & PRTC (available at: www.rcgp.org.uk/revalidation-and-cpd/substance-misuse-and-associated-health/~media/Files/SMAH/Carers-Action-Guide-Second-edition.ashx, accessed on 21 April 2013).

The Princess Royal Trust for Carers (2011) **Evaluation of development of a personalisation course for carers**, Essex, PRTC static.carers.org/files/personalisation-course-interim-evaluation-2012-2-1-6204.pdf

Department of Health (2010) **Carers and personalisation – improving outcomes**, London: The Stationery Office.

Department of Health (2010) **Recognised, valued and supported: next steps for the Carers Strategy**, London: The Stationery Office.

Family Action (2012) **Be Bothered! Making Education Count for Young Carers**, London: Family Action. (available at: www.family-action.org.uk/uploads/documents/Be%20Bothered!%20Make%20Education%20Count%20for%20Young%20Carers.pdf, accessed on 1 April 2013).

Draft Care and Support Bill Cm 8386 (2012), London: The Stationery Office.

Skills for Care (2012), **Carers in your workforce matter**, London: SfC (available at: www.skillsforcare.org.uk/developing_skills/carers/carers_in_your_workforce_matter.aspx, accessed on 28 March 2013).

Think Local Act Personal (TLAP) (2012) **Making it Real: Marking progress towards personalised, community based support**, London: TLAP (available at www.thinklocalactpersonal.org.uk/mir, accessed on 28 March 2013).

