

# Personal Health Budgets

Following Zoe Porter and Alex Fox's overview of the new NHS Personal Health Budgets, we asked our attendees what they would spend their health budgets on. Each guest was given a book of post-its representing a budget of £30,000 to spend on a variety of services throughout the day.

Over the course of the event £1,193,000 worth of post-its were spent. Here are the categories, results and comments from the guests:

## Dementia Friendly Communities – £375,000 spent (31.4%)

### Staying Connected (106 post-its)

- "As I become older and less mobile, don't forget that I am still interested"
- "Person first, dementia second"
- "Champion dementia awareness to local groups"
- "Have coffee and chat with friends"
- "Use already existing community or parish newsletters to put regular information round to involve the public in the topic"
- "Peer support groups and faith group gatherings"
- "Going to the cinema"
- "Social activities that keep me participating in community life, including inter-generational activities"
- "Someone to help me continue going to the theatre, cinema, eating out, and shopping locally"
- "Arts4Dementia will help the development & training for arts activities to stimulate families embarking on their journey with dementia in dementia friendly communities"
- "Taxi fares if I can no longer use my bus pass"
- "Social outings for both drivers (person with dementia) and carers – most carers are partners of drivers and feel isolated"

- "Age appropriate activities for young dementia sufferers"
- "A social group made up of my peers with similar interests"
- "Someone to help me with meeting my friends"
- "Someone to help me access and come with me to community activities"
- "More 'buddies'"
- "To do things that make me smile"
- "To continue to attend church and participate in worship, singing and meetings"

### Maintaining hobbies/activities (99 post-its)

- "Better awareness for people so they don't judge me"
- "Approach universities of the 1/3 age"
- "See [www.arts4dementia.org.uk](http://www.arts4dementia.org.uk) for opportunities for artistic stimulation for families (person and carer) embarking on their journey with dementia"
- "Walking in the park"
- "Fishing"
- "A support worker to take me to the theatre 3 times a year"
- "Meeting friends for dinner in a restaurant/pub"
- "Education – continuing to learn"
- "Free footy for PWD and carer"
- "Knitting groups"
- "Choir"
- "Swimming"
- "Museums"

- "Especially arts based activities to help me maintain my identity and express myself"
- "To continue my passion for cooking"
- "To go out for coffee and cake"
- "Meals out"

### Food and exercise (64 post-its)

- "Highlighting the importance of one's water-based fluid intake"
- "Good idea"
- "Group exercise programmes"
- "Swimming once a week – my physical health is important for my mental health"

### Digital support and technology (34 post-its)

- "No – it is often difficult for people with dementia to use"
- "The tablet – fun, support, connections, information"
- "Skype"
- "A broadband connection so I can keep in touch with friends through social media and email, and for online shopping"

### Getting about (72 post-its)

- "Please preserve the free bus pass! I want one when I'm 65!"
- "I'd like to buy into a community transport scheme for my money to stretch further"
- "Taxis for outings"
- "Trips to Tenby and Cornwall"
- "Trips abroad to the sunshine"
- "Friendly bus drivers"

- "Trips and shopping for both PWD and carer"
- "Accessible transport or a driver to take me to meet friends, to go swimming, to medical appointments, etc."

## Community care and ongoing support - £615,000 spent (51.6%) Carers (80 post-its)

- "Managing the expectations and outcomes for carers"
- "Training of assistants and personal carers: what is the legislation? Who can do what and with which qualification?"
- "Support and advice throughout the pathway"
- "Who checks paid carers?"
- "Support to stay in my own home"
- "Respite breaks"
- "Care for carers"
- "Admiral nurses available to all"
- "Support post diagnosis"
- "Continuity of the carer who comes to my home, not each one someone different"
- "Needs to be relationship centred care at home, not time and task based visits"

## Direct payments to family members (35 post-its)

- "Who checks my payments are being used for me?"
- "For social care and health care?"
- "A good idea but with oversight"

## Adapting your home/ personal belongings (66 post-its)

- "Design for the future"

- "More advice"
- "Wet rooms are a must!"
- "Supporting me to adapt my home even though I don't have a downstairs bathroom"
- "Assistance with hygiene etc if needed"
- "Permit personal care in the kitchen – tell H&S that there's no need for the installation of a downstairs shower! Strip washes are often preferred (warmer)"
- "Commodes with padded seats are better than assisting someone in a small downstairs loo"
- "Changing floor coverings, lighting, and kitchen equipment to make them more appropriate for my needs"
- "It would be great to purchase a package of simple home adaptations and ongoing home support"
- "Assistive technology"
- "How much can I spend to make assistive technology personal technology?"

### Equipment (49 post-its)

- "Be aware that assistive technology is to maintain my well being not to watch me or restrain me"
- "Audio books"
- "Let's be creative with personal technology"
- "Knowledge of what is available! Most carers end up buying items rather than having free loans"
- "PWD lose their learning in the reverse order acquired. How to operate a computer is often the first thing to go"
- "Technology can help in place of some of the abilities a person can struggle with"

## End of life care (101 post-its)

- "End of life care starts long before dying, and continues afterwards"
- "Help generally with this"
- "Let's start the conversation earlier"
- "Training for families in providing care at the end of life"
- "Who tells my dying relative?"
- "Support for my carer. Choice."
- "Don't be afraid to ask me"
- "Help me to organise death certificates, funeral directors etc when I have just lost my relative – is there help?"
- "Emotional support and advice for my carer"
- "Hospice – I would not want it to be assumed that I want to die at home, putting more burden on my carer"
- "Expert advice from a dementia nurse to support care of PWD at home"
- "MSE hospices"

## Respite (97 post-its)

- "Supported breaks with carers and PWD together"
- "Someone to come and stay with me to give my partner a break – why should I have to go into a home for respite?"
- "Respite without guilt"
- "Can this also be two weeks in a 5\* hotel with a paid person while my carer stays at home?"
- "Nursing and holidays – make respite stays special"
- "Crossroads – support carers"

- "Using DPs to buy in replacement care at home for carers' breaks – PWDs in later stages are often frightened of being anywhere except familiar surroundings"

### Therapies & Counselling (69 post-its)

- "We need more hospices involved in helping with the journey"
- "Support groups"
- "More varied counselling that adapts to people's circumstances"
- "For PWD and carers – informal and formal"
- "More counsellors, better access and more Admiral nurses"
- "Physiotherapy and personal trainers (for people with Lewy Body dementias which cause Parkinson's)"
- "Dementia aware?"

### Case management (39 post-its)

- "Named person for contract post-diagnosis"
- "Will spend on this if it is community based and accessible from the home"
- "Led by family carer"
- "Compatible electronic records across disciplines"
- "Care management to make sure my budget works well and I don't run into problems"
- "To make sure everyone is working together"
- "One named person for all case management and advice"
- "Make 'this is me' on one page"
- "Yes to support us with the budget as otherwise organising my person's budget is yet another thing we have to do"

### Prescribing (15 post-its)

- "Only when it is absolutely necessary"
- "Support to make an informed decision (me or my carers) about appropriate medication and alternatives"
- "All medication dosages should be reduced in line with the severity of the dementia. Severe dementia – a paediatric sized dose. Do GPs know this?"
- "Only to help, not to take me away"

### Lasting power of attorney (31 post-its)

- "This should be statutory for all persons of a specific age"
- "Could this be done posthumously to help widows and widowers?"

### Legal/ financial advice (33 post-its)

- "What safeguards personal budgets?"
- "What happens when my money runs out? Do I move to cheaper services and accommodation?"

### Residential care - £114,000 spent (9.6%)

#### Residential care (63 post-its)

- "Someone to help me produce my life story"
- "This needs to be truly individualised, small groups etc"
- "Very, very large residential homes (50+ beds) seem to be being built – how is this person centred?"
- "Someone to support a reading group (like the Readers' Organisation)"
- "More strong drink – less medication"

#### Extra staff (51 post-its)

- "More trained and skilled staff"
- "Not just more staff but the right staff"



- "Skilled staff and more staff"
- "Employ a cleaner so I have a clean flat"
- "Buy a washing and ironing service"
- "Those who are skilled and want to help the PWD live"
- "Paid carers – are they work only focussed?"
- "Better pay for paid carers"

## Hospital care - £50,000 spent (4.2%)

### General hospital care (50 post-its)

- "All hospitals should provide open visiting for relatives"

### Excess Bed days (0 post-its)

## Other - £39,000 spent (3.3%) (39 post-its)

- "Pet schemes"
- "Training for carers"
- "Research"
- "Community nurses and specialist nurses in GP practices"