

Richmond Users Independent Living Scheme (RUILS) is a charity and not-for-profit company limited by guarantee.

It is an independent, grassroots, self-help organisation that is user run and led by its peers – the people who use its services.

Help us to help each other

As a self-help group of individuals who are receiving Direct Payments, we value your knowledge, skills and experience and invite you to share your know-how with others.

For further information about volunteering opportunities or the services and events mentioned here, please contact us at:

RICHMOND USERS INDEPENDENT LIVING SCHEME (RUILS)

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RUILS acts as the champion, representative and peer supporter of all disabled and older people who have social care needs.

It serves those who are in receipt of a Personal Budget or use Direct Payments, Personal Assistants or other means of support to achieve greater independence and well being.

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Tim Mott Associates

Disclaimer

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options

FOR INDEPENDENT LIVING

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'QUALITY, CHOICE AND CONTROL'

In this issue ...

- Choosing a care agency
- I need personalised support – the views of service users

community living alternatives for people with additional support needs

If you would like a copy of this document in large print, Braille, on CD or as a summary in a community language, please contact RUILS. Tel: 0208 831 6083. Email: info@ruils.co.uk

Aby uzyskać kopię niniejszego dokumentu w formacie dużą czcionką, Braille'm, na płycie CD lub w skróconej wersji polskiej, prosimy o kontakt z RUILS.

यदि आपको इस दस्तावेज़ की कॉपी बड़ी लिखाई, ब्रेल में, सी डी पर या हिन्दी में इस का सारांश चाहिए तो कृपया RUILS से संपर्क करें।

Nese keni nevoje qe kopjen e ketij dokumenti te keni me shkronja te medha, ne gjuhen e te verberve (Braille), ne CD ose si permbledhje ne gjuhen shqipe, ju lutemi kontaktoni RUILS.

如果你想得到這份文件的大字體印刷、盲人點字、光碟的版式，或有意索取中文的摘要版本，請跟RUILS聯絡。

اذا كنت ترغب بالحصول على نسخة من هذه الوثيقة مطبوعة بحروف كبيرة او بلغة برايل او على اسطوانة سي دي او ملخص باللغة العربية الرجاء الاتصال ببويلس RUILS .



Welcome

Dear Reader,

In the next few years, it is anticipated that people's expectations will be key to shaping the way social care services are purchased and provided. The so-called 'baby-boomer' generation, who are now entering 'old age', will bring with them a range of expectations which will be more demanding than previous generations.

So, what do people tell us they want? They want control over their lives enabling them, their families and allies, to maintain and improve their well-being and independence - this includes proportionally managing the risks they take. And, they want dignity and respect to be at the heart of any interaction with professionals, so that they can access high quality services and support closer to home and at the right time.

How will homecare agencies respond to these demands? Our headline article 'Are you being served?' (p.04) seeks to explain how they may offer a more personalised service than that which is currently provided.

Direct Payments (DP) were originally promoted by physically disabled people as a way of personalising their support. In this issue we explore different individual's experiences of DP. Page 10 features the experiences of a mental health service user who has found accessing DP difficult but rewarding. On page 11, Elizabeth shares with us her view of living with ME and the benefit that she gets from her Direct Payments. The story of Chris and his parents, as they move on from children to adult services, is described on page 09 and the article 'Parents in the driving seat' (page.07), describes how families of disabled children can get help to use Direct Payments.

Finally, it would be re-miss of us to let this opportunity go without wishing you a happy Christmas and hope that the New Year will offer you the kind and amount of support that you need to live your life as fully, as freely, and with as many choices and opportunities as you can.

The Editorial Team

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EASY-READ GUIDE

Throughout this issue of the 'Options' newsletter, you will find most information is presented in the format you are now reading. There are however, several other types of information which you may find useful. They are displayed in boxes and explained as follows:



Tips & Advice

A box with this image of a lightbulb contains useful tips and ideas provided by experienced service users and practitioners.



Useful Contacts

A box with the image of a telephone contains the contact details of useful people and organizations.



Jargon Buster

A box with the alphabet letters gives a simple description of abbreviations and terms used as shorthand by professionals and others.



Information

These boxes contain extra information or explanation such as government or council advice, what rights you have and what you should expect from other bodies, such as Social Services.

News in brief

Christmas Office Closure

The RUILS office will be closed from Christmas eve until Monday the 4th of January. In preparation for the Christmas break, we would recommend that you talk to your support staff now to make sure that you are covered. If you need extra assistance over the holiday period the earlier that you let Karen or Sarah (of paFinder) know the better. Some agencies will be able to offer temporary cover, but they too will need to know ahead of time.

Financial Monitoring

The new Financial Monitoring Forms are almost ready to be issued and the new process will start in December. If you are new to Direct Payments and Personal Budgets you will have been told by your care manager how frequently you need to complete these forms. For most of you this will be once per year. You complete the form to show the Council what you have been spending your Direct Payment money on. The form and your bank statements need to be sent into the Finance Team - they will tell you when you need to do this. They will take copies of your bank statements and will return them to you. Your care manager will go through this form with you when they meet you for your review.

If you have been using a Direct Payment for some time now, you will have received a letter from the Council advising you that you do not need to submit Forms while they were developing the new system. From the beginning of the new year you will need to start to complete the new form. In the mean time the Council will be writing to you to ask you to send in your Bank Statements for the 31 March 09, 30 June 09 & 30 Sept 09. They do not need to see the full bank statement just the page that has these dates on it. This will enable them to get a snapshot of where you are now. If you need any help with this please contact us at RUILS or contact the Finance team: charginghelpline@Richmond.gov.uk.

RUILS' New Year Survey.

It's not often you get a chance of winning a £50 voucher by making a few marks on piece of paper. But, this will be the reward for two lucky people who complete and return our customer survey.



You will get our questionnaire in the New Year and can return your answers by post or complete it on-line by going to the RUILS website or the office can email you the link.

Please take the time to answer the survey as it is an important way for us to check if we are giving you the right kind of help and advice – and, you never know, it may help pay for a New Year treat!

News In brief

Quick Reminders

- You can spend your Personal Budget on anything as long as it is not gambling or illegal. What you buy must also help you to get the personal support, do those things and achieve the beneficial outcomes that were noted in your self assessment (of needs) and Support Plan. If you're not sure, seek advice before you spend by contacting our helpline.
- You must keep all financial records and bank statements to show how you have spent your Personal Budget (we recommend that you purchase a file to store all your receipts each month in). But, you will only have to submit detailed records or receipts if you are audited by the Council.
- The Council will check (review) the support you buy with your Personal Budget. You will normally have to account for your spending once every year but more often if there is a risk of your support or spending breaking down. You can ask for a Care Manager's review at any time, particularly if your support, health or budget needs change.

Welcome Ben

We are very pleased to welcome Ben Gordon to the RUILS team as our new Helpline Advisor.



Originally from a small town in Warwickshire, Ben moved to Twickenham after school to attend St Mary's University College. While there he studied Media Arts - something he had not studied in the past. Ben's studies meant he learnt many practical aspects of the Media including the representation of disabled people on prime time British television.

Of his new job, Ben says: "I have Muscular Dystrophy and am a full time wheelchair user so researching and campaigning for other disabled people like myself is something I have always enjoyed and put time into. It will be great to hear from you on the helpline and hope that I can use my own experience of living with a disability to good effect."

And also, a big thank you to Charley Youngson who volunteered to stand in until Ben could take up his post. It was a case of learning on-the-job for Charley but she rose to the occasion and has become a much valued part of the team. Thanks again Charley.

Survey of homecare agencies

'YourSay' is a group of 'social care' service users. They have written to local agencies and questioned them about how they will provide a personal service that is tailored to an individual's needs and expectations (see p. 04-06).

We will provide you with this feedback, on our website and in a future editions of Options.

Are you being served?

If you are looking for a homecare agency for yourself, a relative or friend, you'll need to know what they do, how they do it and if the quality of their service is good.

What care agencies do

Homecare agencies normally provide someone to help you with basic personal or practical household task such as:

- washing and dressing,
- bathing or using the toilet
- getting in and out of bed
- cooking, cleaning and laundry
- paying bills and shopping.

They may also be able to provide registered nurses or staff that are trained to work with people who have additional needs, such as dementia, a learning disability or challenging behaviour.

Agencies can deliver temporary, intermittent or long-term support that lasts from say, a fifteen minute 'pop-in' call, to several

hours a day or even 24-hour live-in support.

What agencies charge

If you ask a care agency to provide a support (care) worker, this means you have to pay the agency, but you do not take on any responsibilities as an employer because the person works for the agency.

Most agencies base their charges on how many hours of support are provided, the time and day it occurs and whether the support requires the use of specially qualified staff.

As a very rough guide, local agencies currently (Winter 2009) charge between:

- £13.00- £21.00 per hour, dependent on the above conditions and whether you are a self-funder (pay without any financial help) or use Direct Payments.
- £55 to £80 per night for sleep-in support
- £100 to £125 per night for waking nights

You're advised to get a full quotation of costs before using any agency.

Choosing an agency

We are not all alike, and so an agency that suits one person, would not be acceptable to another.

If you like regularity and routine and you need help with daily-living tasks, then most conventional homecare agencies can satisfy your needs. They are set up to perform the range of

tasks described above and may be your preferred choice if you;

- need only short visits at the same time each day,
- need basic routine tasks to be regularly performed,
- have no great wish to change the way you live or do things differently,
- your situation is stable and your needs remain the same.

If your needs are complex and you prefer a more flexible service, then you may need to look for an agency that can offer a personally tailored response to the: who?, how?, when? and where? of your support. For example;



- Who? (You pick who supports you). The agency offers you an initial trial period of support (at a reduced hourly rate), to help you decide if the support worker is 'right' for you.
- What? (You decide what is done). Agency staff arrives and will do things that are different from the normal routine tasks for that day.

- How and where? (You decide how tasks are carried out and where they happen) e.g. you need to have lunch but also want to go out - your support worker comes with you to the local café rather than giving you a meal at home.
- When? (You choose the time of the call). You want the option to 'bank' some of your agency's hours and carry them over to a week when you need extra help to say, visit your family.

Agencies providing this personalised approach will want to know all about;

- your likes and dislikes,
- your preferred way of doing things,
- those things that are important for you to keep going or re-establish,
- what you can do for yourself, or could still do with the right type of support,
- what you want to achieve or change in your life and what support you need to accomplish them.

They will also demonstrate;

- a willingness to work with other organisations to deliver a mix of support.
- an attitude to risk management that focuses on what you can do with the right support rather than what you can't do,
- a willingness to change their normal ways of working from a task to an outcome-based approach.

Checking the quality

Regardless of your preference for a conventional or person-centred

service, you will want assurance that the agency provides, amongst other things, a service that:

- is reliable and consistent,
- safeguards your well-being and dignity,
- keeps you well informed,
- employs trained staff that have had criminal record checks (CRBs) and are legally employable and
- is well-managed.

You can get an independent measure of quality by consulting the following;

Care Quality Commission.

All home care agencies in England are regulated by the Care Quality Commission. This guarantees certain minimum standards of service.

The websites of the Care Quality Commission (CQC) and the United Kingdom Home Care Association both allow you to search by postcode for a home care agency in your local area. The Care Quality Commission website also contains inspection reports and a star quality rating on individual home care agencies.

Richmond Council. The local authority produces an (approved) list of homecare providers currently used by the Council. Inclusion in this directory is not an endorsement if it is a privately purchased service however, the Council does monitor the quality of Council purchased services.

Other customers. You can gather the views of other service users by posting a request on our internet forum or look at the results of our 'YourSay – Agency Survey'. This records the agency's response

to questions posed by experienced 'social-care' service users.

Your own judgment is as important as any official rating so, before you buy a service, it is advisable to meet the agency. If possible:

- have someone to take notes and to offer a 'second-opinion'.
- check your Support Plan (this describes the support you need),
- prepare a list of questions.

After the meeting, use the following CQC checklist.

- (1) Were the staff helpful in setting out exactly what services they provide?
- (2) Did they explain their costs and charges properly?
- (3) If you are going to pay for your own care, were they willing to give you a blank copy of their contract for you to look at after their visit?
- (4) Were they confident to let you meet and talk to existing clients?
- (5) Did they offer to show you their latest inspection report?
- (6) Did they ask many questions

about you - your likes and dislikes?

(7) Did you get the impression that you would be living your life the way you choose instead of having to fit into their routine?

(8) Did they seem happy to answer all your questions?

If your answer is 'no' to any of these questions, then ask for further clarification or find another agency. Only make your final decision when you are happy that you have all the information you need.

Finally, it has to be said that, with the best will in the world, conventional homecare agencies may, in some respects, find it hard to provide the more personalised service described earlier. This will be a source of disappointment for those of you who are impatient to benefit from having greater personal choice and control. However, if you hold your own Personal Budget, you do have the power of a paying customer and can use this to encourage an agency to provide a more 'made-to-measure' service.



USEFUL CONTACTS

Care Quality Commission. Citygate Gallowgate Newcastle upon Tyne NE1 4PA. **Tel:** 03000 616161.

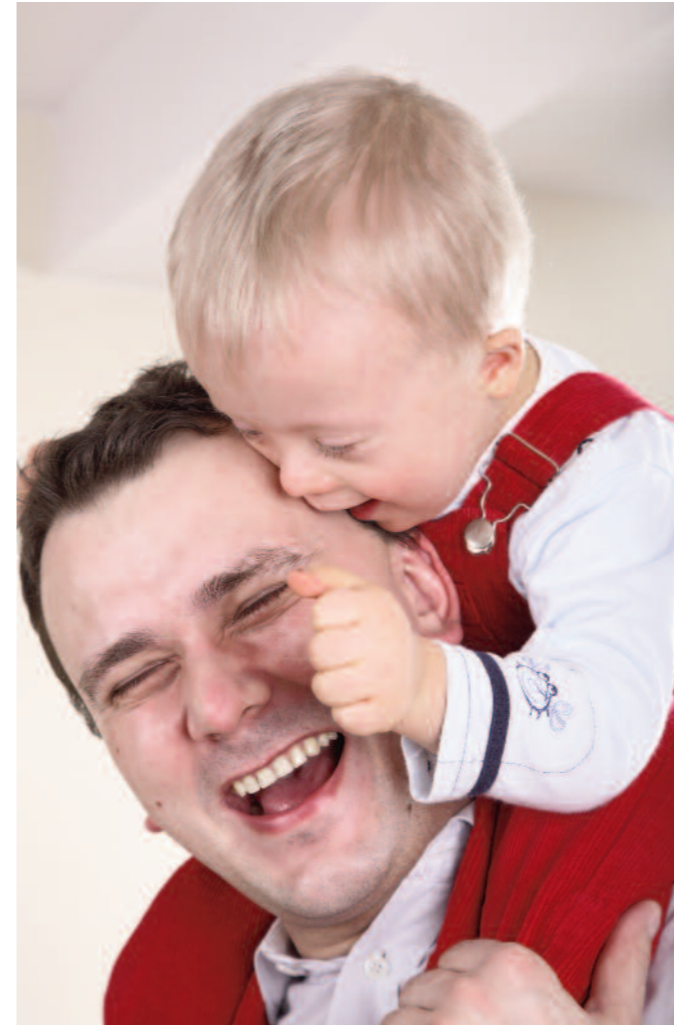
E-mail: enquiries@cqc.org.uk. www.cqc.org.uk.

UK Homcare Association. Group House, 2nd Floor, 52 Sutton Court Road, Sutton, Surrey SM1 4SL **Tel:** 020 8288 5291, **E-mail:** helpline@ukhca.co.uk. www.ukhca.co.uk

RUILS. 'Giving and Sharing' Forum (www.ruils.co.uk), **Tel:** 020 8831 6083), **E-mail:** info@ruils.co.uk. 'YouSay' survey of homecare agencies.

Parents in the driving seat

A reminder to parents of disabled children that Direct Payments are available - and so is help and advice.



Direct Payments are one way in which people can manage their own support by purchasing the assistance or services that the council would otherwise provide. They are available to adults with parental responsibility for a disabled child.

The advantages of this arrangement can be illustrated by families that are currently using Direct Payments to:

- Pay for afterschool childcare where mainstream services are not appropriate,
- Access leisure services e.g. cinema, swimming pool, football club, the Brownies,
- Buy a mobile phone - for a support worker to be able to ring you when they take your child out,

- Hire a hydrotherapy pool - parents are putting their funds together to pay for this.
- Pay a Personal Assistant to:
 - act as 'an extra pair of hands' at busy times of the day e.g. getting ready for school,
 - do household tasks - to free up time for you to be with your child,
 - run a group activity that is set-up by a number of parents with a disabled child

Help to make Direct Payments happen

Here at RUILS we support all parents currently using Direct Payments or who may be thinking about it. We offer a step-by-step approach to exploring their use as well as helping you to continue to manage your payments.

We have experience of helping families to employ their own Personal (care) Assistant or Support Worker using Direct Payments money and can offer you a range of free services including:

- **Home-visiting advisors.** Jackie Jones, Jackie Pilcher and Jane Ayres give one-to-one family support to help you:
 - set up your Direct Payments
 - become an effective employer of your own staff.
 - stay and work with you to resolve any problems that arise,
 - find creative ways to you use your funds,
 - work closely in partnership with you and your social worker,
 - help you find ways you can arrange short-breaks for your child or save up for an activity holiday.
- **Recruitment Pack.** This (soon-to-be published) pack will help you work out what you need to do when employing staff.
- Our 'paFinder' service will help you find a

person that you may wish to employ as a support worker to your child.

- Our **Sharing and Giving** forum (www.ruils.co.uk) is a way for parents to post questions and get solutions that are tried-and-tested by other people who face similar problems.
- Our **Helpline** (020 8831 6083) or E-mail: (info@ruils.co.uk) gives free information and advice on Direct Payments and Self Directed Support.

To help you cut-down on the paperwork, RUILS can also put you in touch with:

- A **Payroll** service that will prepare payslips and work out how much Tax and National Insurance you must pay your staff.

If you have a legal or staff management issue, then RUILS advisors can help you access a:

- **24 hr employment helpline** – available to customers of FISH Insurance.
- **Employer's liability insurance.** Insurance that protects you should your employee injure themselves at work.

Other forms of parental help

There are a growing number of ways for parents of



Useful websites

- www.threewingstrust.org - charity supporting young people with additional needs, and their parents.
- www.metooandco.org.uk - local group offering play and learning activities, information and emotional support.
- www.mumscircle.com - arranges parents to swap babysitting duties in exchange for points.
- www.ncb.org.uk - national 'champion' for well-being of all children and young people across every aspect of their lives.
- www.familiesonline.co.uk - internet family magazine.
- www.mynightoff.com - babysitting network.
- www.workingfamilies.org.uk - advice for working parents, carers and their employers.
- www.cool2care.co.uk - brings together the families of disabled children with trained care-workers.
- www.hmrc.gov.uk/taxcredits/do-you-qualify.htm
- www.direct.gov.uk/en/parents/childcare - comprehensive government website for parents and childcare.

a disabled child to build a network of family support. They include:

- A parent's Facebook friendship and networking group
- The Richmond Parent Carers Action Group - is working to make positive change and have parent's voices heard. www.rpcag.org.uk – Tel: 07946 646033, name of person to call
- 'FamiliesuponThames' - a local magazine to keep you in touch with local information and resources.
Contact editor@familiesuponthames.co.uk
- Family Outreach Project. – Contact Richmond AID Tel: 020 8831 6079 or e-mail w.lam@richmondaid.org.uk
- Crofters Outreach Program - offers a range of clubs and schemes for disabled children. Tel: 020 8831 6044.

We understand that Richmond Council will be writing to everyone using Direct Payments to ask them how they are spending the money. If you need help with this, have a question about whether Direct Payments are right for you or are about to have a Social Service's review of your support arrangements, then do get in touch – we're just a phone call or mouse 'click' away.

Moving on

Self Directed Support for Christopher now he is 18 years old.

Transition is the process of moving through youth to adulthood. Going through transition includes disabled children and their families thinking and planning for the future. Plans can include education, work, maintaining health, housing and support options. Here is one local families account of what moving on has been like, so far



Life can be complicated, especially when you have learning difficulties, are a wheelchair user and have limited mobility plus find it hard to communicate.

Since Christopher has been 15 years old, he has needed a walking frame or wheelchair. He has attended Strathmore School for people with severe learning difficulties since he was 5 years old. He has some speech, some Makaton skills and a heavy portable voice synthesiser box to help people understand what he wants and lives with mum & dad in Twickenham. Our house has been adapted with entry ramps, a lift and social services have provided a support frame for the toilets plus a bath-aid for getting in and out of the bath. Chris likes to be with his friends, many of whom are the same age and with similar challenges. He especially likes eating out, bowling, TV, watching rugby & having a laugh.

When Chris was coming up to his 18th birthday, Social Services undertook an initial review of what care he might need. This consisted of 24 hour care with some respite opportunities for his parents to work and have some leisure time to themselves.

We were recommended to use Advocacy Partners as well, which the local council support. We have had three sessions to establish what Christopher can do & what support he needs for the next twelve months, i.e. until he leaves school. We hope that he will go onto Richmond College and to get a worthwhile occupation through the 'Getting A Life' initiative or similar opportunity.

Written by Dad, Paul, Mum & Jean, with help from Chris.



Useful contacts

- (1) Transitions Development Officer. Richmond Adult and Community Services
Email: Jennifer.Bradbury@richmond.gov.uk Tel: 0208 891 5448
- (2) Advocacy Partners. Transition Team for 16-25 yr. olds with learning disabilities.
Tel: 020 8892 6559.
- (3) 'Getting a Life' www.gettingalife.org.uk Identifies what needs to happen to ensure that young people with severe learning disabilities leave education and go on to achieve paid employment and lead full lives.

Are you with or without?

Direct Payments have existed since 1997. Yet, only a few mental health service users receive them. We asked Amanda, why?

The Government wants Direct Payments (DPs) to become a standard option for mental health service-users. These allow people to receive payments from their local Council to fund services they want rather than be fitted into pre-existing services.

One person who does, is Amanda. She uses them to hire a cleaner and personal assistant to help her get out of the house.

“It’s brilliant and made such a difference. Before, I had no control of my life. I had no choice...It was very important to choose who to work with and say what I needed, rather than everybody else telling me. People think they know you best, but you know you best.”

Others have used Direct Payments for short breaks, gym sessions, driving lessons, work-related training and transport – anything that helps mental recovery.

Take-up has been slow

Mental health service users frequently report problems accessing Direct Payments. “It took a year and a half,” says Amanda. Twickenham resident Amber, waited over two years and as a result set up ‘Taking Control’, a user-led group that hopes to support and ‘signpost’ people to Direct Payments. He says: “All service users I know would benefit from even the smallest amount. Five hundred pounds can change somebody’s world.”

The barriers are various. Social care and health budgets are separate, and mental health workers seem to dislike the idea of user choice. They fear people will take risks and worry they won’t be needed - preferring a personal assistant instead!

“ *A change in the culture of mental health service provision is required. This would need a tangible commitment to promoting self-determination, evident in the way staff interact and support people experiencing mental distress.* ”

Joseph Rowntree Foundation.

Last year, however, a trial of Self Directed Support (SDS) for mental health service users took place in Richmond. Clients, with assistance, assessed their own needs, were allocated Personal Budgets, and created Support Plans. Budgets were paid as Direct Payments or else managed by others.

Amanda is now on SDS. However, she says there are still problems. Her ideas as to what would help her recover can be vetoed if disagreed with. This, many say, defeats the purpose of SDS.

But it’s a step in the right direction at least.



Living with M.E.

People with ME still face ignorance and prejudice but are merely asking to be treated the same as others with long-term conditions. But, let Elizabeth explain....

Myalgic Encephalomyelitis (ME) is also known as chronic fatigue syndrome and can affect anyone at any age and from any ethnic group. The illness is defined by the World Health Organisation as a neurological condition (ICD G93.3). There are an estimated 700 people with ME in the Borough of Richmond of whom 25% are likely to be so severely affected they are housebound or bedbound and in need of care and support. 77% of adults affected have lost their job.

Common symptoms include; abnormal debilitating fatigue, an extreme exhaustion-response to exertion or activity, and long recovery times of days or weeks. People with very severe ME are bed bound and may have to live in darkened rooms. They experience difficulty in swallowing, moving, speaking and extreme pain, which can include multi joint pain and severe headaches. Noise, light

and movement can all contribute to sensory overload as the brain tries to analyse each and every sound, rather than ignoring repeated sounds as it does in unaffected individuals. For people with severe ME, sitting up, answering questions, digesting and going to the toilet can all be over-activity.

Managing ME

Rest is the cornerstone to stabilising the condition and any chance of improvement. Even very minor activity must be spaced with rest periods. Traditional ME carers are trained to encourage the client do as much as possible for themselves, but this can be disastrous for someone with ME as it often leads to increased disability. People with ME are the only ones who know where their limitations lie and how much they can do without exacerbating their symptoms.

“ As an older, single woman, even on one of my best days, living on my own presents daily challenges and keeps me almost housebound. I have become increasingly sensitive to light, sound, chemicals and certain foods. My ability to talk in a conversation or use the phone is limited to about quarter of an hour.

For me almost-daily support funded by Direct Payments is my lifeline. Outwardly to onlookers I may appear relatively well. So, maintaining the right working relationship with helpers/PAs is difficult as they don't realise just how ill I am nor how much rest and quiet I need. Employing PAs for as little as 1 hour, the amount I can cope with, is hard. When they work in my flat, some carers do not like having to refrain from using perfumed products, such as handcream and soap, before they visit me. It is difficult finding good English speakers able to work relatively unsupervised from a written list, who can be depended upon to be reliable. However, such a person when found, can be like arms, legs and voice for me! ”



Useful contacts

Richmond and Kingston ME Group are a self-help group supporting and providing information to people with ME. They aim to reduce the isolation experienced by people with ME through a newsletter, a helpline, and an email chat group. They are also involved in publicising ME, and in campaigning for better local and domiciliary services and to this end the group are currently carrying out a survey of all our members to provide much needed data on their specific needs.

E-mail: skip812-rkmeigroup@yahoo.co.uk **Tel:** 07984 860 309 (ansaphone).

Internet: <http://www.richmondandkingstonmeigroup.org.uk>