

What do I want to do?

a DIY guide to self-assessment for Disabled people

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Introduction

This is the first in a series of short guides to be produced by the Gateshead Personal Assistance Pilot Project. The Guides provide information and advice to Disabled people in Gateshead who wish to live independently by using Personal Assistance.

Independent Living

At the heart of Independent Living is the principle that Disabled people should have full choice and control over all aspects of their own lives. This means control not only in managing tasks such as eating and washing but also in other areas of life such as having personal relationships, working or having fun.

Personal Assistance

Personal Assistance is about the rights of Disabled people who require physical support (from a Personal Assistant) to be able to buy, manage and control enough of that support (Personal Assistance) to lead as full and spontaneous a life as a non-disabled person.

Self-Assessment

This Guide then aims to provide a Disabled person with the tools to assess their own Personal Assistance needs:

- what do you want to do in your life?

- what do you have difficulty doing?
- what kind of help will enable you to do these things?

You will find an example of an Assessment Checklist, a discussion about preferences and lifestyle and a sample Job Outline.

More information

Future Guides to be produced by the Gateshead Personal Assistance Pilot Project will look at sources of funding for Personal Assistance; the recruitment and employment of Personal Assistants; advice for both Disabled people as employers and for Personal Assistants as employees.

See the last section of this Guide for who to contact for more information, advice or support regarding Personal Assistance.

Personal Assistance Needs

Assessing your own Personal Assistance needs

Before you think about actually employing your own Personal Assistant (PA), you need to work out what your personal assistance needs are. The most straightforward way is to keep a checklist or diary over a period of a month of everything that you need assistance with. It should be a 24-hour record to include overnight assistance.

There are three main areas to consider:

Personal needs - things like getting up and going to bed, washing, eating, bowel and bladder care and so on.

Domestic needs - shopping, laundry, child care, household tasks, driving and so on.

Social needs - getting to work, studying, having fun, going to meetings and so on.

For every activity you need to record:

- what assistance you need;
- at what time;
- for how long;
- how often (hourly, daily, weekly, monthly).

It is important not to underestimate the amount or type of assistance that you need. In particular, make sure you include **everything** that family and friends do for you now.

Don't forget that you will also need to include all the things that you would like to do but can't do at the moment because you don't do or struggle to do because you don't like to

keep asking a family member to do them for you.

Don't forget that you will also need to include all the things that you would like to do but can't do at the moment because you don't have personal assistance! Or those things that you don't do or struggle to do because you don't like to keep asking a family member to do them for you.

Make a 'wish' list, decide how often you want to do something and for how long and add it to your checklist.

Don't forget, Personal Assistance is about choice and control so your checklist should state **your** needs, what **you** want to do and **when** you want to do it.

To help you along, we have included an example of a checklist that has been used by other people. You can use this or design your own.

Once you've written down the assistance you get now and the assistance you want to get in the future, you can then start to sort out more easily your Personal Assistance needs:

- what times of the day do you need assistance - daytime only, nighttime only, morning and evening only and so on;
- do you need assistance around the clock;
- do you need assistance every day, weekdays only or odd days for specific activities;
- do you only need assistance in your home or wherever you are;
- do you always need assistance for the same specific set of tasks, such as getting up and going to bed, or do you need assistance for a wide range of tasks;
- could some things be done more easily with the right equipment;

Every activity need not be done by just one person or always carried out in the same way. You may decide that you want a Personal Assistant in the mornings and evenings, a cleaner coming in for one day a week and that your child will go to a nursery every weekday afternoon.

Checklists:

Assistance needed	yes/no	Time of day (a.m./p.m.)	How many minutes	How often: hourly, daily, weekly, etc.	Your comments
Personal needs:					
Getting up					
Medication					
Washing face					
Washing upper body					

Washing lower body					
Washing hair					
Menstrual hygiene					
Shaving					
Body hair removed					
Nails clipped					
Feet care					
Skin care					
Eye care					
Ear care					
Combing/brushing hair					
Dressing for day					
Positioning in wheelchair					
Medication during day					
Moved to rest position					
Assist with exercise					
Physiotherapy					
Assist in or out of car					
Toileting					
Undressing for bed					
Washing					
Teeth cleaning					
Night medication					
Dressing for bed					
Settling down					
Moving in night					

Assistance needed	yes/no	Time of day (a.m./p.m.)	How many minutes	How often: hourly, daily, weekly, etc.	Your comments
Domestic needs:					
Tea/Coffee making					
Preparing breakfast					
Preparing lunch					
Preparing tea					
Cooking meals					
Assistance with eating					
Accompanied shopping					
Getting prescriptions					
Storing food					
Laying tables					
Lighting fires					
Making/changing beds					
Washing dishes					
Washing laundry					
Ironing					
Mending clothes					
Hoovering & dusting					
General cleaning					
Managing heating					
Gardening					
House repairs					
Vehicle maintenance					
Wheelchair maintenance					
Upkeep of equipment					
Child care					
Pet care					

Assistance needed	yes/no	Time of day (a.m./p.m.)	How many minutes	How often: hourly, daily, weekly, etc.	Your comments
Social needs:					
Advocacy					
Communication					
Companionship					
Getting to work					
Getting to College					
Studying at home					
With my hobby					
Using my computer					
Using my music system					
Using TV and radio					
Managing bills & money					
Household paperwork					
Personal paperwork					
Socialising					
Going to meetings					

The Lifestyle that you want

If you are going to be bringing a Personal Assistant into your life, you need to think about the lifestyle that you want to have.

Working with a personal assistant is a very personal and intense relationship and you need to be clear about the things that are important to you.

Laying down guidelines or 'house rules' at the start will help to prevent problems in the future.

Use this checklist as a general guide to help you get started:

- Does it matter if your PA smokes
- Is a tidy home important to you
- Do you like your home to be quiet
- Are there programmes on TV you must watch
- Is religion important to you
- Are you willing/able to delegate some tasks
- Do you prefer to have set routines
- Do you always want to get up at the same time
- Do you like planning meals
- Do you object to meat eating
- Do you normally prefer to eat on your own
- Do you enjoy choosing what you wear
- Is your personal appearance important to you
- Do you mind other people using your personal items
- Do you want to entertain at home
- Do you want friends to stay overnight

This is not an exhaustive list, just a few ideas to start you off. Add your own thoughts here....

Job Outline

Once you have identified your Personal Assistance needs and have thought about the way that you want to live your life, you will be in a position to put together a job outline for prospective Personal Assistants.

To give you an idea of the kind of things you could include, here is an example of one produced by someone who lives locally.

Introduction

I broke my neck in a traffic accident 30 years ago when I was 20. I have little movement or sensation below my shoulders. I can however move my arms but have no sensation or movement in my hands.

I am able to do many things around the house but I do require assistance with most aspects of daily living. I always require someone to be available during the mornings and

evenings but, depending on my personal activities, may not always need someone to be around in the afternoons.

I would normally use an electric wheelchair for which I need assistance getting in and out off, but can control unaided. When necessary, say when I know access will be difficult, I use a manual wheelchair and will require pushing. I have a Possum environmental control system in the house which allows me to use and control a variety of electrical equipment.

I would prefer my personal needs to be met by a female and I need them to be reliable, flexible and to respect my privacy and confidences. I need to take medication at regular intervals throughout the day but this is usually in pill form and requires no special techniques to administer.

Personal needs

Regular

I need turned first thing in the morning, around 8am. I am given my medication and have a drink in bed. Every other day I need suppositories followed, approximately an hour later, by a manual bowel evacuation. Around mid-morning, I start the process of getting up. Whilst still in bed, I have my lower half washed. I need my skin checked at this point for any red marks indicating pressure. I then have my lower half dressed, which includes changing and attaching my drainage bag. I need assistance to get out of bed and into my wheelchair using a sling and overhead hoist. I go to the bathroom and have my upper half washed. I brush my own teeth but need assistance with putting toothpaste onto the brush. I then shave. I use an electric razor and can shave most of my face unaided but need assistance to finish off. I am now ready to have my upper half dressed and my hair combed. Lastly, I have my glasses put on. At lunch time, I need assistance with medication and have a sandwich and hot drink. At intervals, throughout the day, I may need my drainage bag emptied. About mid-afternoon I have another round of medication, again accompanied by a drink. I like to have my main meal and further medication between 5pm and 6pm and require assistance with this. I like to go to bed at about 11pm. Just before this time, I have my final medication and drink for the day. I wash my own face and brush my teeth but, again, I need assistance putting the toothpaste on. I then need my top half undressed and, using the sling and hoist, I am transferred on to the bed. I have my bottom half undressed, my day drainage bag clipped to the side of the bed and the night bag plugged in. In order to sleep, I need pillows arranging so that I am comfortable, I can usually sleep throughout the night without the need for assistance but there are times when I may need some help.

Less regularly

I would like to have a full bath at least once a week. I have a bath sling and hoist. I like to have my hair washed twice a week. I arrange for a hairdresser to come and cut my hair every eight weeks. I have finger and toe nails cut as necessary. I have my drainage changed twice a week. It has happened, rarely, that my bowels don't behave as expected and I would need assistance with cleaning up.

Domestic needs

Once I am up in the morning, I deal with my post. I need the envelopes opened and the correspondence removing but I can physically manage and read my mail. I use my computer to print letters, envelopes, cheques and so on. I need assistance with preparing items for signing and sealing envelopes and, at times, with changing floppy discs and

general fetching and carrying of books and papers to do with projects I am working on. Although not on a special diet I am a fussy eater with very specific tastes (basically I don't like food) and I like to decide what I will eat. However I am not interested in shopping! For all meals, assistance is needed with laying tables, preparing food, clearing away, washing up and storing plates, cutlery, pots, pans etc. I also need personal assistance with eating food. Assistance is needed with all general household tasks such as laundry, ironing, storing, hoovering, dusting and cleaning. I am not a fanatic about tidiness but I like the place to be kept clean. I own a van and would require driving on a fairly regular basis. I would need simple maintenance carried out on both the van and the wheelchair.

Social needs

I like to go out in my van visiting places of interest as often as the mood takes me. I like to visit my local pub, and sometimes to travel further afield, and need assistance with drinking! I am the chair of a local voluntary organisation and I visit the office on two afternoons a week as well as one evening every two months. I am interested in military history and would like to travel to other parts of the country to visit museums, record offices and the like.

Your next steps

You should now be in a better position to decide if you want to control and manage your own Personal Assistance.

It may be that having looked at your needs you feel that they can be best served in some other way, perhaps through the use of equipment, via services provided by the Social or Health Services or by using one of the many Home Care agencies.

If you'd like to explore personal assistance further you need to think about:

Funding-

how will you pay for your personal assistance package? Possible sources include Disability Living Allowance, Social Services, the Independent Living Fund, personal finances and so on.

Recruitment-

where will you find a personal assistant(s)? You will need to think about advertising, drawing up a job description and interviewing potential assistants.

Employment-

once you have recruited someone, you will need to provide a contract of employment, pay wages and national insurance and manage your personal assistants on a regular basis. Don't panic! There is a wealth of experience out there that you can tap in to, both from individuals who have employed their own personal assistants and organisations which have been established to provide advice and information.

More information

If you live or work in the borough of **Gateshead** and you would like more information about Personal Assistance please contact:

Gateshead Personal Assistance Pilot Project

John Haswell House
8/9 Gladstone Terrace
Gateshead
NE8 4DY

(0191) 477 3558 (voice)
(0191) 478 4082 (minicom)
(0191) 477 1260 (fax)
gpapp@disabilitygateshead.org.uk (e-mail)

If you live outside of Gateshead and you would like more information about Personal Assistance or details of your nearest project please contact:

National Centre for Independent Living

250 Kennington Lane
London
SE11 5RD
0171 587 1663 (voice)
0171 587 1177 (minicom)
0171 582 2469 (fax)

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Funded By

GPAPP is a project of Gateshead Council on Disability. Gateshead Council on Disability is a Registered Charity no: 700677 and a Company Limited by Guarantee registered in England no: 2216540. Registered Office: 8/9 Gladstone Terrace, Gateshead NE8 4DY.

"We need to be clear what we mean by independence. We are not talking about being able to do everything for

yourself. Neither does it imply cutting oneself off from the assistance of others.

For what matters is not whether you do something with or without the help of others, but that it gets done under your direction.

Being independent simply means that you have some control over your life, and that you do not live by the routine of others."

Simon Brisenden

"A case of human rights".