

Disability Benefits -

Disability Living Allowance Attendance Allowance and the Personal Independence Payment

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DLA and AA Disability Living Allowance and Attendance Allowance

Disability Living Allowance and Attendance Allowance are the two most important benefits for people with any sort of longer-term illness or disability - including mental health problems. They are, broadly speaking, 'extra' money for people who don't manage 'well' when left to their own devices - either because of difficulties looking after themselves, communicating and socialising, or because of some sort of 'risk'.

Before 1992 there *was* a benefit to help with care coats but qualification was based on assessment by a doctor and far fewer people got help. The introduction of DLA and self assessment extended entitlement to people with 'lesser' care and mobility needs and recognised the value of listening to people's own experiences of coping with long term illness and disability.

In the field of mental health, it has been a longer, harder struggle. For one thing the original DLA and AA forms offered few helpful prompts for people trying to convey their mental health problems. Additionally, until the 'Mallinson' case in the late 1990s, significant awards of DLA and AA were usually limited to people who met 'serious risk to self or others' criteria.

The Mallinson case was revolutionary, ruling that encouragement, verbal support, prompting or reminding which was 'reasonably' required counted towards DLA and AA, opening up disability benefits to thousands whose lives were disrupted by mental health problems. The 'Halliday' case in 1997 built on this, ruling that help with social activity and hobbies counted too.

So why, then, are people still turned down for benefits they should undoubtedly receive? Why do welfare rights workers still have to warn people it's 'a bit of a lottery' when helping out with initial applications? Part of the problem still lies with poor adjudication - the DWP may have all the information but still sometimes get the decision wrong. Certainly they often seem to award grudging Lower Care when Middle Care is actually indicated by the application.

Problems are also caused by a move back to the bad old days when doctors had the final say in who did and didn't get benefit. Presumably in the name of 'fraud prevention', the DWP now seem to seek 'further' evidence far more than they used to, which is fine as long as there's someone fully aware of the claimant's difficulties to provide it.

But whilst GPs/ Psychiatrists may well wish to support an application, the wording of the questions on the 'factual statements' they are sent doesn't actually relate to where DLA caselaw is today: the questions are phrased in very black and white terms - can someone do something or can't they - and have few prompts to remind the person completing it to consider the verbal and psychological support someone might need. The same problem applies to the forms completed by visiting doctors - which means that the DWP end up with incomplete evidence which they then use to support bad decisions.

Speak to the 'public face' of the DWP and they seem to recognise that in the world of mental health, applicants may well have little contact with their GP, or may find it hard to open up to a complete stranger who comes to interview them... yet they continue to gather information which leads to a patchy picture at best.

I, then, work hard to gather supporting evidence to enclose *with* the initial claim - even if it takes a bit of extra effort and time - in the hope that it will be processed successfully without the DWP feeling the need to seek any more information. I also try to make sure that if they do, they go to the best person to provide it - read on!

Problems with completing the forms are also still significant; At best it's a long and depressing process - at worst an insurmountable hurdle, leading to significant under claiming. In spite of this I'm not in favour of greatly shortening them. To make a proper decision the DWP need the information they ask for. What *is* undoubtedly needed are more sources of help and advice with completing the forms - and decent, correct adjudication when they are submitted.

The increasing use of ESA medical reports when DLA decisions are made is a worrying trend - see the pages on 'Personal Independence Payment - the future of DLA' towards the end of the chapter for more on this.

If you're filling in the forms on your own behalf, may whatever support you need in that process either lie within these pages or be accessible to you - and good luck! The same applies if you're helping someone to fill forms in; sadly there is no magic formula and 'professional' involvement is no guarantee of success.

But today, *when caselaw is properly interpreted and applied by the DWP and medical evidence has not been contradictory*, awards of AA and the equivalent middle and higher rate care components of DLA along with lower mobility are now quite usual for people experiencing difficulties surrounding anxiety, depression etc. as well as for those with 'more serious' mental health labels.

Bad decisions continue to need challenging, but whilst the process is far from perfect, awards of AA and DLA are still changing lives and, in so doing, supporting good mental health.

The future, sadly, looks a lot less certain, with the Government's pledge to replace DLA with a benefit which will involve medical assessment taking us back full circle to the days before DLA was born. *'You can use 'Plus ça change' as a section heading'* said my benefits advisor partner as I was re-writing this section. *'I already used it under ESA'* I answered. Plus ça change indeed...

Why are DLA and AA such Wonderful Things?

"Raindrops on roses and whiskers on kittens...."

Now it might seem slightly odd that anyone should get so excited about a benefit that sometimes requires a good couple of hours of form filling to claim, but ask a welfare rights worker to name their 'favourite' benefit and chances are they'll choose DLA, mention Attendance Allowance and their eyes start to mist over... Why?

Well, it's because time and time again we've seen the difference that getting DLA or AA can make to people's lives. Many recipients describe it as being the difference between 'surviving' and 'living'.

Both benefits have a flexibility which is unusual in the system - most benefits are taken away

pound for pound, penny for penny from any means-tested entitlement - meaning that they make little or no difference to the people who need them most.

DLA and AA are different though - not only are they always extra income in themselves, for people whose means are limited, they often trigger extra means-tested entitlement...

Their recognition that someone may have difficulties but still be able to work is also refreshing within a system which otherwise seeks to brand people with a 'yes' or 'no'. DLA and AA - with their varying rates - at least recognise that health is a continuum - a sliding scale.

- ☺ You can get and keep them in or out of work
- ☺ They're not means-tested in any way
- ☺ They're paid on top of any ANY other income
- ☺ They'll NEVER mean a cut in any other benefit
- ☺ They might mean MORE help through other benefits
- ☺ They can entitle carers to benefits
- ☺ There are no restrictions on how they're spent, enabling people to make the choices that make the biggest difference to *their* quality of life.



So what's the difference between DLA and AA?

Basically very little! The major differences are that the two benefits serve different age groups and the rather illogical lack of help with 'mobility' for older people.

Each benefit has a qualifying period, so older people have to put up with their difficulties for 6 months before they can be paid whilst those under 65 can qualify after 3 months.

DLA	AA
Claimed by people under 65	Claimed by people of 65 and over
Difficulties must have lasted for the previous 3 months and be likely to last for next 6 months	Difficulties must have lasted for the previous 6 months
Two 'components' - care and mobility	Only care needs addressed
Five weekly rates: Lower mobility or Higher mobility and/or one of: Lower care Middle care Higher care	Two weekly rates, with the same value as the middle and higher care components of DLA: Lower rate Higher rate

People who are awarded DLA before their 65th birthday can carry on being paid both (or either) care or mobility element of it indefinitely, as long as they continue to meet the qualifying criteria.

Children and DLA

The DLA care component can be claimed for children at birth (even though it won't be paid for three months). The higher mobility component can be claimed from a child's third birthday or the lower mobility component from their fifth birthday.

Because all young children will need *some* degree of help and supervision whether they're unwell or not, to get either the lower mobility element or *any* care element you have to show that their needs for help or supervision are 'substantially in excess' of those that another child of the same age without the illness or disability would have.

It may help to get together with a parent of another child of the same age to chat about their child's level of 'need'

Difficulties associated with claiming DLA for children with mental health issues also arise because it can be hard to differentiate between a 'phase' they're going through and behavioural problems.

It can also be difficult to get diagnoses, and not easy to get good supporting evidence because schools and therapists will often be keen to emphasise the progress children are making, not their difficulties.

If your child has physical, behavioural or mental health problems, any good advice agency should be able to help with a claim for Disability Living Allowance.



What do the regulations say?

DLA Mobility Component - Higher Rate

Someone must have a PHYSICAL disablement and their PHYSICAL CONDITION as a whole must be such that they are:

- ⇒ Unable to walk; or
- ⇒ Virtually unable to walk; or
- ⇒ The exertion needed to walk would constitute a danger to life or be likely to lead to a serious deterioration in health; or
- ⇒ They have no feet (from birth or through amputation)

OR someone must be:

- ⇒ Blind; or
- ⇒ Be getting DLA care at the highest rate AND be severely mentally impaired from 'arrested development of the brain' (see below) AND have severe behavioural problems needing constant supervision to avoid danger to self, others or property (i.e. get DLA Higher Care).

These conditions rule out the higher mobility component for most people with mental health problems unless they **also** have brain injuries, or learning or physical disabilities that make it very difficult or dangerous for them to walk.

Caselaw defines 'Severely Mentally Impaired' as having an IQ of 55 or less, BUT says a common sense approach should be taken...e.g. where social functioning restricts the application of otherwise higher intelligence - as with some people with autism - or where there is no sense of common danger... 'Arrested or Incomplete Brain Development' means before the brain is fully developed - i.e. before the age of 30.



DLA Mobility Component - Lower Rate

The Lower rate mobility component is payable to people who are able to walk outdoors but - *ignoring familiar routes* - can only use this ability with guidance or supervision from another person.



Regulations introduced in 2002 sought to make receipt of the lower mobility component more closely linked to diagnosis of a 'severe mental disability' - or so said the then Government's press releases. The example used by the Government was that someone diagnosed with agoraphobia could continue to qualify whereas someone whose anxiety and fear stemmed from a fear of losing control of their bladder when outdoors would not.



What the new regulations actually said is that where fear or anxiety prevents people from walking in unfamiliar places, they will NOT qualify for lower mobility UNLESS 'the fear and anxiety is a symptom of a mental disability and is so severe as to prevent the person from taking advantage of the faculty in such circumstances'.....so it's actually the *fear and anxiety* that has to be severe, *not* the mental health problem...

My experience since the new regulations were introduced is that they have had no discernible impact on the number of people receiving awards of lower mobility - presumably because the vast majority of the people I've worked with *do* have a mental health basis to their difficulties walking.

Tactically, the only difference it's made is that if someone mentions *also* being anxious about incontinence - or some other non-mental health related concern associated with being outdoors - we have a chat about why it might not be advisable to include the information in their claim... just in case it muddies the waters in the decision maker's eyes...

What do the regulations say? (DLA Care/ AA)

FOR ANY AA or DLA MIDDLE/HIGHER CARE

<p>BY DAY:</p> <p>The need for frequent attention throughout the day in connection with bodily functions</p>  <p>AND/OR</p> <p>Continual supervision throughout the day to avoid substantial danger to themselves or others</p>	<p>BY NIGHT:</p> <p>The need for prolonged or repeated attention in connection with bodily functions</p>  <p>AND/OR</p> <p>Another person to be awake for a prolonged period OR at frequent intervals for the purpose of watching over them to avoid substantial danger to themselves/ others</p>
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Difficulties JUST during the day or JUST at night =
DLA MIDDLE CARE COMPONENT/ LOWER RATE AA
 Difficulties day AND night =
DLA HIGHER CARE COMPONENT/ HIGHER RATE AA

FOR DLA LOWER RATE CARE

<p>⇒ Attention for a significant portion of the day whether during a single period or a number of periods OR</p> <p>⇒ That they are unable to prepare a cooked main meal for themselves, given the ingredients. Children under 16 cannot qualify through this route.</p>
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What do these regulations actually mean?

Over the years, caselaw has ‘interpreted’ what is meant by the terms used above. What has emerged then - when most sympathetically applied - is a rather more precise definition:

Daytime:

- difficulty with personal care/ medication/ thinking/ communicating/ socialising three or more times, spread through the day AND/OR
- there being some sort of serious-ish risk if someone doesn’t keep an eye on you through the day

Night-time:

- difficulty with personal care/medication/ thinking/ communication more than once or for longer than 20 minutes at night AND/OR
- there being some sort of serious-ish risk if someone doesn’t keep an eye on you three times or more, or for more than 20 minutes at night

Lower care:

- difficulty - amounting to about an hour in total - that isn’t spread through the day but is concentrated during a single period/ a number of periods

More caselaw...

Caselaw is established by:

- the DWP, or
- the applicant (or an advisor on an applicants' behalf)

taking appeal decisions they feel to be wrong 'in law' on to be heard by the 'Judges of the Upper Tribunal' (which sound much more scary than the 'Social Security Commissioners they used to be known as) or even ultimately to the House of Lords...

The resulting decisions then set 'caselaw' precedent which DWP decision makers and Tribunals are theoretically bound by. Sometimes they need reminding of what caselaw says!

There's a massive amount of caselaw that only advisors are every likely to want to use, but it can be handy to know what it says about the basic qualifying conditions when filling in a form, or trying to decide whether a seemingly bad decision needs challenging.

'severely disabled'

The DLA Care/AA conditions start with the idea that someone has to be "so severely disabled that..." For a while the DWP tried to rule out some people as not being "severely disabled", but caselaw says that in this context, all it means is that someone is *sufficiently* disabled that they qualify for a disability benefit - i.e. they meet one or more of the qualifying conditions.

I suspect this argument will also be tried by the DWP within ESA tribunals - and needs challenging on precisely the above grounds.

'requires help'

Lots of argument over this. The DWP have, at various times, argued that:

- help must be medically required - e.g. that someone could be left in a wet bed unless they had a skin condition that would be worsened by the urine... Caselaw says no, it only has to be *reasonably* required
- you could avoid the need for help by being sensible and staying in a chair all day to avoid falls, or be locked in your room if you tend to wander off - but caselaw says no, any restrictions must be reasonably compatible with a 'normal' life

- help has to be for "essential" things, not merely "desirable" things - NO said the House of Lords. In the 'Fairey/ Halliday' case they ruled that someone reasonably requires any help 'which as far as possible enables them to lead a 'normal' life' - *including* social and leisure activities.

You don't *need* to be getting any help at all - it only has to be reasonably required, not provided. However, where help *is* actually provided, caselaw says that it is strong evidence that it is required - argue that hard pressed carers or cash strapped mental health services don't provide help just for fun!

'attention' or 'supervision'?

Caselaw says that **Attention** is an *active* service involving contact with someone else to enable you to deal with personal care tasks. It can be physical - but it has also been ruled that non-physical contact, like someone speaking to you or supervising an activity counts too (the 'Mallinson' case). The attention must be needed in person - e.g. encouragement by telephone wouldn't count.

Attention has to be "**in connection with bodily functions**" - this means closely connected with personal care (e.g. washing, dressing, seeing, communicating, eating, etc.) as opposed to 'domestic duties' like shopping, cleaning etc. But help with domestic tasks *can* count if you can involve another bodily function - e.g. help with the bodily function of seeing, or thinking *whilst* shopping. Similarly, difficulties being able to care for others - e.g. children, another adult - count too.

Supervision is more *passive* - 'it might be precautionary or anticipatory, yet never result in active intervention', says caselaw. It's more about guarding against the risks of harm - such as self-harm, self neglect, being aggressive to others or provoking aggression in them. It could be given by someone who is doing something else - it certainly doesn't mean someone sitting watching you 24/7.



How long for?

Attention:

“attention for a significant portion of the day” (DLA Care Lower Rate)

This applies if you don't have needs at frequent intervals *throughout* the day but only for a portion of it - about an hour or several shorter periods adding up to an hour, says caselaw.

“frequent. attention throughout the day” (Daytime rules for AA, or DLA Care - Higher or Middle Rate)

Caselaw says this means several times, not just once or twice, whilst 'throughout' means spread over the day. The spread doesn't have to be even - someone might have most difficulty first thing in the morning, but as long as they could do with some help during the rest of the day they might satisfy this condition, rather than the lesser attention condition for Lower Care.

There is a certain amount of overlap between the Lower Care “significant portion” (especially when spread over several occasions) and the daytime “frequently ...throughout” condition for Middle Care - e.g. someone needing help for just 5 minutes at 3 to 4 hourly intervals during the day quite clearly meets the 'frequent attention throughout the day' condition for Middle Care even though the amount of care needed only amounts to about half an hour.

Needless to say, the DWP often seem to start at the bottom and work up, awarding Lower Care rather than considering this only if someone *doesn't* meet the “frequent throughout” condition which would give Middle Rate. Caselaw says this is *wrong* - they should start by looking for Middle Care - challenge those decisions!

“prolonged or repeated... by night” (Night-time rules AA, or DLA Care at Higher or Middle Rate)

As far as night time needs go, caselaw says that 'prolonged' means 20 minutes or more and 'repeated' simply means more than once. Remember this is an 'or' rather than an 'and' requirement!

Supervision:

The supervision conditions are tougher in that there is no route to lower rate DLA Care, the supervision has to be required for longer than attention does, and there must be 'risk' to self or others.

“continual...throughout the day” (Daytime rules for AA, or DLA Care - Higher or Middle Rate)

Not continuous, but most of the time throughout the day - with only limited breaks - not longer than an hour.

“frequent or prolonged watching over at night” (Night-time rules for AA, or DLA Care - Higher or Middle Rate)

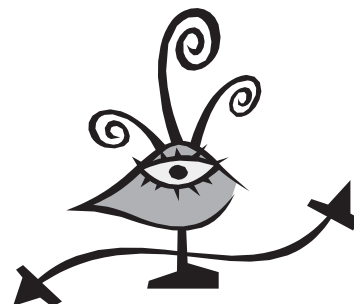
Caselaw says frequent means several times, not just once or twice - so arguably three could count. Prolonged means 20 minutes or more and watching over means being *awake* to watch over.

Other Supervision issues:

How is supervision provided?

Being supervised **doesn't** mean someone constantly staring at you! It could be someone being available in case you need to call for help or need checking on - in a different room or even a different house, as long as they are close enough to intervene.

One ruling that really upset the DWP was that someone could even be supervising whilst asleep if they were attuned enough to someone's difficulties to wake when needed. As a result the DWP promptly changed the night time rules to stop a flood of claims, so that at night you *do* now have to need someone to be “awake for the purposes of watching over” you.



How do you show that supervision is required?

Caselaw has established a four part test for supervision needs:

- ◆ **Is there a substantial risk from a potential danger?** Substantial means big - but not necessarily life threatening. The DWP were ruled wrong not to count the risk of biting the tongue in a fit and for dismissing suicide attempts that were clearly not meant to succeed. The risk could well be relatively minor in terms of 'life and limb' as in some self-harm, or a longer term one, such as that of self neglect. Supervision must only *reduce* the risk of danger, not necessarily eliminate it.
- ◆ **Is it reasonable to guard against the danger?** Caselaw says that the actual 'incident' being guarded against may have only happened once or even not at all - it's obviously not reasonable for example to wait for a deaf person to get knocked down three or four times before you accept that they might need supervision to keep safe in traffic! In general, the more serious the risk, the less often it needs to arise. It can be useful then to include any history of 'incidents' - suicide attempts, detention under section, accidents etc. to show likelihood, but don't be put off even if an incident has never, to date occurred!
- ◆ **The supervision must be reasonably required** - but not medically required
- ◆ **The supervision must be required continually (daytime) or at frequent intervals/ for a prolonged period (at night).** You can argue that even though you are reasonably 'well' between bouts of more serious problems, you may still need supervision - e.g. to ensure you stick to their medication, are not becoming unwell again, do not neglect to care for yourself, eat regularly, etc.

The fact that you may not be getting any supervision does NOT mean that you don't reasonably require it - so remember to think of what would be useful and not to concentrate solely on any limited supervision you might actually be getting.

Variability...

Caselaw tells Decision Makers that they should take a 'broad view' of conditions that vary or fluctuate. In reality though, needs people have 3 days a week or less will probably be ignored (unless they concern the 'cooking test').

Try, then, to answer in the context of 'How many days a week... might some difficulty occur? How predictable is this? How predictable is the variability? Might you have a bad day *any* day (and so be likely to need help any day)?

Conditions that fluctuate over a longer period - e.g. bi-polar disorder, or schizophrenia may need more 'explaining' on the forms. Although it's probably easy to fulfil the conditions for benefit when things are at their worst, it may be more difficult *between* these times. Make sure then to include *any* difficulties experienced most of the time - e.g.

'Even when I'm a bit better, I still find it really hard to make myself do things and rely on my family to push me to look after myself... I still have paranoid thoughts even though the voices aren't there...'

What you are effectively doing here is saying that even when you don't need supervision you still need the encouragement, prompting etc. needed to fulfil the 'attention' conditions.

If you are absolutely fine between bouts of being unwell, you may have to rely on explaining why you need supervision because your condition can deteriorate very rapidly, or because you try to hide the symptoms from others, or don't accept that you are unwell etc... see the section on 'Supervision' questions later in this chapter.



The 'Special Rules' for people with life-threatening conditions

People suffering from potentially life threatening illnesses can be 'fast tracked' through DLA/AA applications using what are known as the 'Special Rules'. It should take just 10 days.

The same rules will also fast-track an applicant to the Support Component within ESA.

To qualify under Special Rules, someone has to have a progressive illness from which they could be 'reasonably expected' to die within six months. This doesn't mean that the doctor or specialist providing evidence for the claim thinks that the individual involved *will* die within six months and Caselaw has defined the test to be one of whether 'death would not be *unexpected* within six months'.

Claims which suggest someone might fall under the Special Rules, but where the 'Special Rules Box' has not been ticked, will be treated under the Special Rules.

To qualify this way, a 'DS1500' certificate has to be submitted, completed by a GP or Specialist, detailing someone's diagnosis and treatment. It does *not* ask about the individual's prognosis. At hospitals providing treatment to people with life threatening conditions, specialist nurses and social workers are familiar with the processes and will often make enquiries/ arrange this certification on someone's behalf. Claims through the Special Rules can also be made without the potential benefit recipient's knowledge.

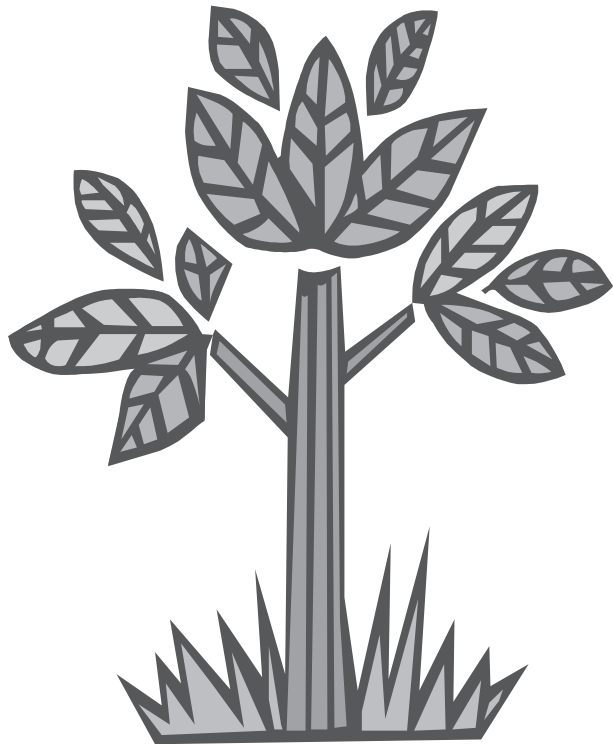
You don't have to complete the parts of the form relating to 'Care' if you are applying under the Special Rules, but if you have mobility problems (either physical or mental health related) then you will need to complete that section.

People ARE sometimes turned down in spite of submitting a DS1500, but this is unusual and - of course - appealable.

Awards will be paid at the highest rate care component of DLA or AA. Once indefinite, new awards of DLA/ AA made under the provision for Special Rules are now for a 3 year fixed

period, at the end of which time the award is reviewed. The fact that someone has survived three years should not be taken into account when reviewed and the test is the same - would death not be unexpected in the next 6 months?

People with claims made before July 2006 who are still claiming seven years after a claim was made under the Special Rules will have their cases looked at again at this time.



Renal Dialysis

Anyone needing two or more sessions a week of dialysis and attention or supervision from someone else in connection with this treatment **AUTOMATICALLY** qualifies for the DLA middle care component or the lower rate of AA, provided the dialysis takes place at home or as an out patient without assistance or supervision from hospital staff.

Remember however that someone qualifying on the basis of needing renal dialysis may also have mobility difficulties, or may be entitled to the higher rate of Care if they also fulfil the night-time conditions.

Information about these needs will still need to be supplied on claim forms.

Completing the Forms

In general...

- ✎ Whether you're filling in your own form or helping someone else, allow plenty of time - gathering the information to complete an entire form can often take a couple of hours, sometimes more. If you're doing your own, try to arrange to do something more cheerful afterwards! Advisors speed up a bit because they become more familiar with the layout of the form, but many also feel that having the form in front of them whilst speaking to someone and trying to do tidy handwriting at the same time can actively get in the way. You can always take detailed notes whilst going through the 'difficulties' and fill the form in later.
- ✎ If you're helping with a form, remember there can be a fine line between encouraging someone to 'have a go' and creating unrealistic expectations. *You* might know that someone ought to get lower rate mobility and middle rate care once their form is submitted, but the more DLA or AA applications you get involved with, the more you realise that the only truly predictable thing about them is the unpredictability of the decision making process!
- ✎ Being turned down is always upsetting but can also feel very personal, especially as the DWP use a coldly phrased standard rejection letter simply quoting the law back at you. Remember that the DWP can and do get it wrong first time!
- ✎ Once the form has been sent off, a standard 'we have got your form....if we want more information we might write to you or ask a doctor to call...' letter is sent out. This doesn't mean that a doctor **WILL** visit. These visits *rarely* happened with applications based on mental health problems alone. It's worth considering though the albeit remote possibility of a DWP doctor being asked to call to see you in your home.

✎ You don't **HAVE** to see the DWP doctor if you don't want to, but if you want your claim to be dealt with fairly, you'll have to convince the DWP you have a good reason. If you feel very strongly that you couldn't cope even with company then say so - if possible also getting a supporting letter to this effect. If you're helping someone with a claim and are in a position to offer supporting evidence, it can make a huge difference to do so - if only in that the DWP and their doctors aren't famous for their understanding of mental health issues! Try to explain in a letter to accompany the claim why an EMP's visit would be particularly inappropriate - e.g. if the person concerned would find this particularly stressful or threatening, or if he or she has particular difficulties with communicating with strangers, or is likely to deny or underestimate their difficulties when questioned.

✎ If the DWP do decide to send an EMP round, you will be given a date in writing in advance and can ask for someone you know to be there too. It's a good idea for any companion to take notes on what is being asked and what is replied, what sort of physical examination or walking test was carried out, how long the examination lasted etc. *Don't* be intimidated (easy to say, I know!) Copies of an EMP's report can be requested from the DWP.

✎ If you have more than one 'problem' - e.g. arthritis, falls, depression, high blood pressure - it can be useful to take a few moments to list **ALL** your problems on a scrap of paper and keep it in front of you whilst you're working, to make sure you think about each problem as it relates to every page.



Extra Considerations for Advisers:

- ✎ Remember to stress the confidentiality aspect of the interview. If the information gathered *will* be available to other people in or outside your organisation, then it is good welfare rights practice to explain this at the outset. Involve the person you're working with in deciding who to ask for supporting information, whether or not to approach their GP, etc. In my old work setting *all* the information gathered was confidential unless something was said which made us actively fear for that person's, or somebody else's immediate safety. Wherever it felt possible, we would discuss the action we intended taking before doing so.
- ✎ The start of an interview can be a very anxious time for someone new to your service. Making 'small talk' is NOT a waste of time in this context!
- ✎ Remember that being forced to concentrate on difficulties can be extremely depressing for people - be prepared to stop, offer support and leave things for another day if needs be. A box of tissues, access to cups of coffee, or even a cigarette break can be useful!
- ✎ For similar reasons, I try to deal with the most sensitive questions - e.g. the ones about suicide, self-harm, aggression etc earlier in the interview rather than later. Not the moment people walk in of course... but so that there's still time to lift the mood a bit...
- ✎ You - and your employers/ organisation - should also recognise that *gathering* the very personal and detailed information demanded for a DLA or AA application in a sensitive way can be stressful and at times distressing for the interviewer too, especially if issues which have a personal resonance for them arise. If you find it hard to deal with your feelings after an interview, share them. It's *not* a weakness and it *is* possible to talk to someone else about how you are feeling without breaking confidentiality.
- ✎ Don't dismiss any of the sections of the form out of hand, even when you know people well. One social worker was quite amazed to discover that her client was extremely distressed at the idea of using the toilet and was, as a consequence, severely limiting her intake of fluids.
- ✎ Negative questioning tends to result in negative answers. Say 'you don't have any problems getting out of bed do you?' to someone and they're quite likely to agree with you! Always try to keep your questions open, offer suggestions of the *sorts* of difficulties people might encounter - think laterally and don't confine yourself to asking just what's on the form.
- ✎ Remember too that if people have had stays in hospital against their will in the past, or worry about the thought of having to go into care, or 'into a home', it can be very difficult for them to be wholly honest about the difficulties they experience. This can also be a particular issue for parents who fear that admitting to any difficulties looking after their children might lead to their being taken into care. You may find it helps to reassure people that 'the Social' *isn't* the same as Social Services and that the idea is to access extra money so that they will have more choices and resources to help them cope in the future.

Having said all this, try to prepare beforehand for the fact that someone *may* say something to you during an interview which causes you to be concerned for their immediate safety, or for the safety of someone else. Discuss this possibility beforehand in your organisation, so that you are confident of how to handle this situation should it arise. Many workplaces already have policies surrounding these issues.



Down to brass tacks:

The 'administrative' questions

As well as wanting information about your health, DLA and AA forms also ask a lot of administrative questions: date of birth, nationality, GP, hospital doctor etc.

- In spite of their urging otherwise, you may want to ignore the box that asks for your telephone number - you won't be pulled up for not giving it and if the DWP need more information, they can always write for it. This will mean that if things go wrong, you have a paper record of all the information relevant to your claim.
- When filling in the boxes about who you see in connection with your health, remember that hierarchical and medicalised ideas prevail in terms of how the DWP will 'value' supporting evidence from others! Therefore a very supportive friend will carry less 'clout' in their eyes than for example a fairly supportive CPN or Drop-in worker. The CPN would also carry more weight in the DWP's eyes than the Drop-in worker because they have a medical tag.
- Although DLA and AA are both meant to be based on self-assessment, and any help considered only reasonably, not medically required, the DWP sometimes write to people's GPs for very dry 'factual reports' once an application for benefit is made. This causes particular problems in the world of mental health where GPs are often not very involved and people's continuing contact tends to be with CPNs, Social Workers, Support Workers, Drop-in staff, Psychologists, Counsellors or Psychiatrists. If your relationship with your GP is limited - or bad - then consider not giving their name and address where asked for it and instead, writing in 'I see my (CPN, counsellor etc...) about my mental health, not my GP'. The worst the DWP can do is write back asking for that information, but in my experience they never have... Happily it seems that they too are starting to accept that people's continuing contact may well *not* be with their GP.
- Where the form asks for details of medication/ tablets etc remember to include
 - ⇒ depot' injections
 - ⇒ ECT (past or present)
 - ⇒ counselling
 - ⇒ seeing psychiatrist
 - ⇒ occupational therapy
 - ⇒ art therapy
 - ⇒ group therapy
 - ⇒ attendance at day hospital
 - ⇒ attendance at drop-ins
 - ⇒ support group membership
- If someone is not on medication because they refuse it, I also try to point this out.
- The forms put a heavy emphasis on 'diagnosis' yet caselaw says that you can still get DLA even if you *don't* have a diagnosis - it's having the problems that should count. If you're unsure what your diagnosis is, you could just put 'mental health problems' and go on to describe your difficulties as best as you can.
- The consent page has raised a lot of questions about who it is reasonable for the DWP (and others) to have access to in connection with your medical and other history. The wording is so broad that many people I've worked with have expressed unwillingness to sign - and yet to refuse permission altogether seems to be inviting a claim to be turned down or an DWP doctor to be sent out to assess the claim. As a compromise then, I've been doing lots of crossing out and inserting, so that the consent given simply authorises the DWP to contact the people the claimant feels happy about them talking to - e.g. CPN, psychiatrist, Drop-in worker etc. Nobody's told me off yet...



Mobility Component: (DLA only) - Higher Rate

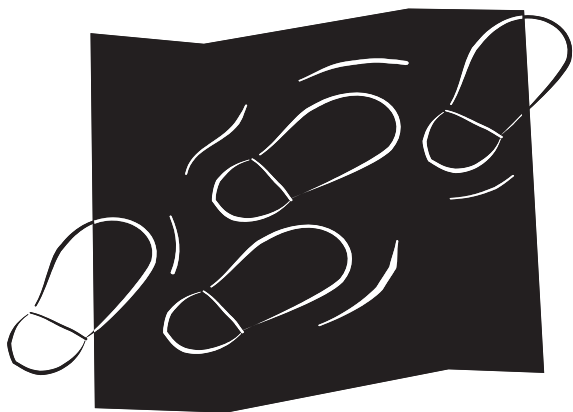
The DLA claim form devotes three pages to Higher Mobility .

As mentioned earlier, it is *almost* impossible to achieve an award of higher rate mobility in the absence of a PHYSICAL problem, learning disability or behavioural problem. There is however one route that *some* people with *some* mental health problems, brain injuries or learning disabilities can take to the Higher rate of the Mobility Component. To qualify you must:

- get DLA care at the highest rate AND be severely mentally impaired due to ‘arrested development of the brain’ AND have severe behavioural problems needing constant supervision to avoid danger to self, others or property (further details under ‘regulations’ earlier in this chapter)

You can understand then why few people actually get it! But the DLA form makes absolutely *no* mention of this potential entitlement, guiding people who don’t have a physical problem with walking straight onto the questions on lower mobility! Whoops!

Very few higher rate mobility awards are now made without the DWP sending a visiting doctor (often with seemingly limited mental health awareness) round to assess the whole claim, so unless you’re fairly convinced that you have a very good chance of qualifying, it may be as well to put nothing down on these pages.



Although the form only asks about difficulties you have walking on a ‘reasonably flat surface’, there *is* caselaw which says that some degree of gradient **MUST** be considered.

- Estimate the distance you can walk **WITHOUT** severe discomfort, **NOT** the absolute limit of your walking ability. Very few people can come straight out with a number of yards or meters when trying to answer this question - it’s often easiest to think of ‘from where to where’ you can manage and then get someone to pace it out for you.
- Remember to detail any dangers that the effort of walking might cause or worsen (e.g. asthma attacks, angina) along with any difficulties with balance, breathlessness, discomfort, pain, etc.



The question which asks ‘*Do you fall or stumble when walking outdoors?*’ may also be relevant for people whose walking difficulties have a mental health basis e.g. someone with epilepsy, or alcohol dependency may stumble/ fall, or you might do so as a result of your mental health problem making you less aware of your surroundings. This can also apply indoors - as in question 40 later in the form,

If this is the case, say so, but make it clear that the difficulties have a mental health basis - to try to avoid an unnecessary call from the DWP doctor. It can help in this section to explain why any falls or stumbles cannot be predicted (and thus avoided). There is, thankfully, caselaw that says that it’s not reasonable to expect someone to sit in a chair all day to avoid the risk of falling!

If the shock/ stress of falling could bring on or worsen another medical problem - e.g. asthma, angina, hypertension etc. remember to say so. If you suffer from some condition which means you have difficulty getting up, bleed or bruise easily, or would be at added risk from falling (e.g. due to osteoporosis, or being on blood-thinning drugs) mention this as well. If previous falls have resulted in injury, say so.

Mobility Component (DLA only) - Lower Rate

Before going further, be aware that the section on 'Falls or Stumbles' you've just been guided past by the DWP could be relevant to you - see the previous page.

Having someone with you when outdoors

Tick any boxes that might apply but DON'T be tempted to think that that is enough. Try to explain ALL the difficulties you might have and how having someone with you helps (e.g. encouragement, guidance, communicating with strangers, reassurance, keeping from danger, calming, helping you to a place you feel safe, etc) - see the lists below and on the following pages for suggestions.

DLA caselaw says that your ability to walk outdoors should ignore 'familiar routes', so if you cope with getting to see friends/ relatives, or to some local shops and back alone, that shouldn't stop you getting benefit. Try to imagine how you would cope in an *unfamiliar* setting, and answer the questions in that context.

Incredibly, if your difficulties are so severe that you can't get out at all, then some caselaw would say that you do not qualify because you 'cannot enjoy the enhanced facilities for locomotion'. This translates as 'you can't benefit from being awarded the lower rate Mobility Component' rather than anything to do with trains!

However there *has* been a helpful Commissioner's Decision which said that someone managing to get as far as their garden gate could be therapeutic enough in itself and counted as being 'outdoors'.



When I am outside I feel so frightened/ anxious/ nervous/ scared/ worked up that....

◇ I cross the road to avoid people/ get away (- often not checking to see if it's safe first)	◇ I can't use the bus or a train to get away - shut in with all those people
◇ If someone comes on to talk to me I feel like I'm going to die	◇ I've had to leave shops without the things I wanted to buy
◇ I can't take in what people are saying to me - I just nod automatically and all the time I'm thinking 'go away'.	◇ I just have to get out/ away - it doesn't matter who's in the way
◇ I can't approach other people for directions, or to ask things	◇ Because I'm concentrating so hard on just coping, I end up forgetting what I wanted
◇ I can't cope with strangers/ I can't cope with meeting people I know	◇ I have had to return home and go without things I needed
◇ I feel as if I've no right to be there	◇ I feel really threatened/ irritated/ angry by other people around me
◇ I feel as if other people are watching me	◇ I get terribly worked up if I've got to wait or queue for anything
◇ I feel trapped	◇ I have to do things like go back and touch things, or not step on the cracks on the pavement to keep safe
◇ Everything feels unreal - like I'm watching a film	

When the panic attacks happen...

◇ I can't breathe	◇ I feel the blood draining away from my head
◇ I get giddy	◇ I feel/ am nauseous/ sick
◇ I have to sit down	◇ My stomach lurches
◇ I faint	◇ I sometimes lose control of my bladder/ bowels
◇ I have hurt myself falling	◇ I get frozen to the spot
◇ I feel hot	◇ I just have to get away
◇ I feel cold	◇ People around me get frightened
◇ I start shaking/ trembling	◇ I don't take any notice of what's going on around me
◇ My heart starts pounding	◇ It can bring my asthma/ angina on
◇ It's very frightening	◇ I've had to abandon my shopping
◇ I feel like I'm having a heart attack	
◇ I feel like I'm dying	
◇ I get tearful/ start crying	

...because of this I have to have someone with me (all the time/ in places I don't know well) to make sure that I am safe/ help me concentrate (think straight)/ reassure me/ guide me to somewhere where I can calm down/ talk me through my breathing/ reassure other people)

Because of my mental health problems...

◇ I am phobic about.... this means that...	◇ I believe that I can do things that are really dangerous like...
◇ the voices/ things I see distract me and make it hard to concentrate on what's going on	◇ I get urges to set fire to things
◇ the voices make me so scared that I have to get away	◇ I think I can stop the traffic
◇ the voices tell me to hurt myself / others	◇ I feel more important than usual
◇ I feel that other people want to harm me	◇ I dress in ways that make people react to me (differently? aggressively?)
◇ I have gone after people I think want to hurt me to get them first	◇ I throw myself at complete strangers
◇ I feel in danger of hurting other people	◇ other people say I could get hurt
◇ I have hurt other people	◇ I'm much less inhibited than usual
◇ I have had to be taken home/ to hospital/ to the police station	◇ I spend money I haven't got
◇ people find it hard to understand me because I say strange things	◇ I do things like go into police stations and tell them I have committed crimes
◇ I have hurt myself	◇ I tell them other people are trying to hurt/ kill me
◇ I have tried to kill myself	
◇ I have thought about killing myself	
◇ I have gone off without telling anyone else and stayed away for... (days? weeks? months?)	



... because of this I need someone with me to reassure me/ keep an eye on me/ make sure that I do not hurt myself/ make sure I do not hurt someone else/ make sure that I don't put myself/ others at risk...

DLA Care Component/ Attendance Allowance

Most of the Attendance Allowance questions - and the 'care component' questions for DLA - follow a very similar pattern.

The 'Attention' questions -

i.e. ones that start 'do you usually have difficulty or do you need help with':



By 'usually' the DWP mean more than half the time - i.e. on at least half the occasions you attempt something/ at *least* three and a half days a week. Happily the form no longer demands to know how many days a week you have difficulties on every page! You may have spells of being relatively well between more debilitating periods of ill health but this doesn't mean that you don't have *some* continuing difficulties on a day-to-day basis. Put down the number of days that *some* difficulty occurs, not just when things are at their worst. Decision Makers will ignore needs that you have less than half the time.



Most pages also ask 'how often' you need help with something. Again either have a careful think and estimate, or try keeping a sort of 'diary' over a few days. If your needs are unpredictable and you could have difficulties at any time, then the answer is probably 'throughout'



Don't get too hung up on the 'how long each time' questions! Most people have no idea how long something takes, so either estimate - '15 to 20 minutes/ up to 30 minutes' etc. or try timing yourself. When estimating times, it is easy to underestimate - do remember to look at every aspect of an activity - getting up, for example, for someone with depression, arthritis and vertigo, may involve:

- waking
- stretching gently whilst lying down to ease stiffness and pain,
- slowly turning onto their side to enable them to push themselves up using their 'good' arm,
- help to get a pillow behind them to prop them up,
- having a cup of tea brought up by a partner,
- being reminded to take tablets and then encouraged to get out of bed,
- using hands to lift arthritic legs out of bed,
- sitting on the edge to 'come to' for a few minutes, then
- using a bedside cabinet to push on whilst standing up and finally
- taking a minute or two to 'ease' themselves a bit before walking to the bathroom
- they may also need to go back to bed during the day to rest - and then have difficulties getting up again in the afternoon too.



Don't assume that simply filling in the 'how often?' and 'how long each time?' boxes will be enough to get the message across - use the box below to explain your difficulty or need for help, stressing if it needs to be repeated and detailing what happens if it isn't - e.g. 'My mother has to call me repeatedly in the mornings - otherwise I would just lie in bed until mid day. It's not that I'm lazy, it's just that the effort of getting up feels too much. When I'm very unwell I sometimes stay in bed all day because I feel safer there...'



If there is any question that lack of prompting, encouraging and reminding could lead you to neglect yourself or put your health at risk then say so... 'my Counsellor says that unless I eat regularly I will become unwell.... When I went into hospital I had lost two stone...'



Remember any indirect needs too - 'It's not enough for my brother to tell me to change - he has to run the bath and find clean clothes for me... otherwise I just don't bother.'



👉 Don't limit yourself to the exact questions they ask on the forms - e.g. you may need encouragement NOT to be so active or NOT to wash over-regularly etc. If in doubt, put it in - on a separate piece of paper if you run out of space. What you're aiming at is as comprehensive as possible a picture of how your difficulties affect you. Completed forms aren't right or wrong, it's just that some are more 'complete' than others.

👉 When physical difficulties are involved, describe any pain, slowness or unsteadiness involved even if you manage the task without help. Detail any ways in which physical and mental problems impact on each other e.g. - *'when I'm 'up' I charge around without stopping and my angina gets a lot worse'*.

👉 Most of the pages ask about difficulties with 'personal care' activities but problems with communication/ dealing with paperwork also counts towards DLA and AA and there's a whole page on the forms devoted to the sorts of difficulties someone might have. Many mental health problems result in communication difficulties - don't forget to include things like being anxious about answering the phone or opening and dealing with the post, fear of strangers, difficulties taking things in/ remembering them due to lack of self confidence, anxiety, etc. Also mention the therapeutic value of being able to socialise, etc. and the negative impact of isolation on any mental health problems.

👉 'Thinking' now also definitely counts as a bodily function for DLA and AA - they've even had a 'tribunal of commissioners' look at this specific question and they've given it the thumbs up. But sadly the forms make no reference to this whatsoever. Of course you can use the 'any other information you'd like to tell us' spaces to describe any difficulties you have with thinking and how others can help you with it, but it shouldn't be down to claimants having to 'guess' what might and might not count. Come on DWP - pull your fingers out and design forms that actually reflect the conditions for receiving benefit... or are you just too busy thinking about it?

👉 Again, although there is no mention of it on DLA or AA forms, it's very hard to see why sexual activity wouldn't count as a bodily function - and problems in this area are quite common within the field of mental health. When it comes up within an interview, I include the information on the form - either under 'help with your care needs during the night' or, less conservatively, on the hobbies/ interests/ social or religious activities page. Using the latter gets round having to consider 'how often?' and 'how long each time?' question! Remember that the encouragement must need to be given in person, not over the phone...

NOTE:

At the time of writing, the quality of decision-making on benefit applications based purely on 'encouragement, reminding, telling' - type attention still seems mixed. Although in many cases these needs quite clearly amount to 'frequent attention throughout the day', people are sometimes still being awarded only the lower rate of Care or even turned down altogether.

I've also seen Decision Makers dismiss prompting and encouragement because it is adjudged that there is no risk involved!! Some Decision Makers then seem to be interpreting the need for 'encouragement, reminding and telling' as *supervision* rather than *attention* conditions. It seems likely that we will have to keep telling and reminding them that they're wrong!

Other (or the same!) Decision Makers often seem to take it upon themselves to decide that although help is provided, or may be preferred, it is not actually *required*. If this happens, try to get or provide supporting evidence from a third party categorically saying it *is* reasonably needed.



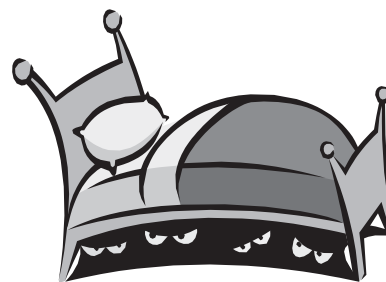
Getting out of/ into bed

People's difficulties are usually either extreme of:
not wanting to get out of bed / returning to bed (only place I feel safe, can't face the world/ can't face the day)

OR

avoiding going to bed/ unable to stay in bed

(the voices are worse at night/ I'm terrified of dying in my sleep/ I dread the nightmares/ the anxiety just gets worse and worse - I have to get up and do something)



Difficulty sleeping is a symptom of many mental health problems, and many mental health problems feel worse at night. The need to be calmed to a state where you might be able to sleep can count towards DLA/ AA.

Caselaw says that 'night-time' can be said to begin 'when the household would normally shut down'
OR be between 11.00pm and 7.00am – argue whichever definition is most useful!

◇ I can't make myself get up without someone encouraging/ pushing me	◇ If I go wrong I have to start again
◇ I sleep very badly so feel shattered when I wake up	◇ For example if a stair creaks then I have to go downstairs and start again. It can take hours
◇ I'm worrying about something before I'm awake properly	◇ I take my tablets downstairs because I want to be almost asleep by the time I go up
◇ I wake with my stomach churning	◇ Because of this I have gone up/ fallen asleep downstairs:
◇ I don't want to get up - bed feels safer	⇒ with a lighted cigarette burning in my hand
◇ I just want to shut myself off from the world/ other people	⇒ and got very cold
◇ I go back to bed as soon as I'm alone/ during the day	⇒ with the fire full on
◇ I can't stay in bed - as soon as I'm awake I have to be up, doing things	⇒ without putting the guard round the fire
◇ I feel more anxious/ scared at night - I stay up until I'm exhausted	◇ I feel terribly down as darkness falls, and often just sit there, unable to make myself go up
◇ Day and night feel just the same - sometimes I'm up all night and in bed all day	◇ If I know I have to go somewhere the next morning I'll stay awake all night
◇ I'm awake all night pacing round	◇ When I'm 'up', I don't sleep at all and when I'm down, I just stay in bed
◇ The voices seem worse/ louder/ more frightening at night - they stop me sleeping	◇ I sleep in the hallway so that if someone tries to get in I'll know that they're there straight away
◇ Sometimes they tell me to get up/ hurt myself etc.	◇ Going to bed/ sleep doesn't feel 'safe' - it's at night that they try and get you
◇ I feel I have to check everything over and over again before I go to bed - it can take ages...	◇ I am terrified of dying in my sleep
◇ I feel I have to do things in a certain order to keep safe before I can go to bed	◇ I am terrified of the dark and can't get out of bed unless it is light

Because of this I need (repeated?) encouragement/ prompting/ reassurance/ shouting at/ persuasion to get up/ stay up/ go to bed/ stay in bed.

Toilet needs

<ul style="list-style-type: none"> ◇ When I'm really anxious/ panicky I lose control of my bladder/ bowels ◇ I get so upset I need help to clean myself up afterwards ◇ The anxiety makes my Irritable Bowel Syndrome worse. Someone reassuring and calming me can help. 	<ul style="list-style-type: none"> ◇ I get bouts of vomiting because of anxiety ◇ Going to the toilet upsets me/ makes me feel dirty so I limit the amount of liquid I drink to a bare minimum ◇ After I've been to the toilet I feel I have to wash and wash afterwards - I sometimes can't stop without reassurance
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Washing/ bathing/ shaving/ looking after your appearance

MOSTLY 'encouragement/ reminding' type problems but OCD can lead to over washing/ showering/ bathing - sometimes a certain number of times, sometimes completely out of control, sometimes has to be started again if not done 'right', sometimes done with abrasive cloths/ brushes/ disinfectant/ bleach. This can both lead to skin problems and prevent other activities

People with psychotic illnesses sometimes avoid mirrors

<ul style="list-style-type: none"> ◇ I just don't care any more ◇ I can go for days/ weeks without bothering to wash/ bath/ shave/ wash my hair ◇ I feel ashamed but I can't make myself ◇ I'm meant to put things for my eczema in the bath, but then I can't make myself bath ◇ I feel safer if I'm looking unattractive ◇ I'm terrified by the water ◇ I just want to be left alone, but my partner goes on and on at me ◇ I feel I have to wash/ bath over and over again - but I still don't feel 'clean' 	<ul style="list-style-type: none"> ◇ I have to wash my hands a certain number of times before I can move on ◇ All the washing is bad for my skin/ eczema ◇ I don't think about washing or how I look ◇ Sometimes I think that parts of my body change - I get distressed when I'm washing ◇ I don't use/ change sanitary protection ◇ I don't get rid of used sanitary protection ◇ I won't look into mirrors because you see bad things in them ◇ I shaved all my hair off to find the bad mark (or similar)
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Because of this I need lots of prompting/ encouragement/ reminding/ nagging/ reassurance/ help to enable me to deal with hygiene/ the way I look.

Dressing/ undressing

again MOSTLY 'encouragement' type problems

BUT

- Some people are so consumed by worries / self doubt they cannot 'choose' what to wear
- Bipolar disorder (Manic Depression) can lead to flamboyant/ inappropriate dressing that can attract (unwanted) attention
- Dressing can also be sexually provocative (particularly dangerous if someone becomes sexually disinhibited or generally vulnerable/ easily 'led')
- Some people are very reluctant to undress at all (won't change/ go swimming/ to the doctor etc.)
- Some people with dementia-type problems might remove clothing or dress inappropriately/ unsuitably for the weather



Dressing/ undressing (continued)

◇ I stay in my night-clothes all morning/ day	◇ I often go to bed without undressing
◇ I can't make the effort to change - I put the same things on day in, day out.	◇ I won't take all of my clothes off at the same time; bathing is impossible
◇ Because of the shakes/ tremor I often spill things. My partner end up pointing it out and persuading me to go and change	◇ I'm terrified of taking my clothes off so won't go to the doctor when I'm ill
◇ When I'm 'up' I dress very flamboyantly - it makes people look at me and laugh/ have a go/ try to take advantage	◇ I took all my clothes off in the street
◇ I stop thinking 'do I need warm clothes today?' - I end up getting very cold	◇ I was going to leave the world as I entered it, naked
	◇ My anxiety means I cannot make decisions about what to put on; I have sat on the bed surrounded by clothes crying my eyes out

Because of this I need a lot of encouragement/ persuasion to get dressed/ undressed/ need someone to check that I'm properly/ cleanly dressed.

Moving around indoors

Many people don't complete this page at all! Difficulties are usually either extreme of:

- sitting doing nothing (or going back to bed) due to depression/ obsessive worries/ intrusive thoughts/ negative symptoms of schizophrenia/ side effects of medication
- OR being unable to sit down/ pacing/ obsessively checking, cleaning/ trashing things etc (due to OCD, anxiety, elation, paranoia, agitation, anger). This can result in exhaustion.

◇ I feel so down I can't get off the settee	◇ I can't switch off from my thoughts/ worries
◇ It can go dark and I'll still be sitting there	◇ I cry a lot
◇ I spend hours staring out of the window	◇ I plan how I'm going to end it all
◇ I keep the curtains shut all day to keep the world out	◇ I spend my day waiting for something terrible to happen
◇ I can have the TV on but I'm not really taking it in	◇ The voices distract me from what I'm doing
◇ I don't do anything	◇ I pace around the house all day but I'm not really achieving anything
◇ My concentration just goes if I try to do something	◇ I have to be cleaning every minute - I exhaust myself
◇ I just stay in my bed/ bedroom	◇ I think my neighbours want to hurt me, and spend my day listening to their movements
◇ I won't answer the telephone	◇ I feel people come in and move things, and spend my day trying to put them back
◇ If someone knocks the door I pretend not to be there	◇ I spend all day in my room, waiting for them to come and hurt me
◇ I get 'stuck' in the checking/ rituals I feel I have to do to keep safe unless there's someone there telling me it's OK. This can go on for hours.	◇ I see faces in the wallpaper/ nets, and spend hours watching them
◇ My mind is just blank - empty	◇ I see faces in the wallpaper/ nets, and spend hours watching them
◇ I get flashbacks/ horrible thoughts that stop me thinking about what I'm doing	◇ When I lose it, I trash the place

Because of this I need someone to reassure me, tell me it's all right/ encourage me to do things

Falls/ stumbles - see previous section on falls under Higher Mobility

Cutting up food, eating and drinking

Can be the need for ‘encouraging/ pushing’ linked to appetite loss - e.g. anxiety and depression - but can also be:

- encouraging someone to eat healthy food/ not ‘comfort’ eat/ binge
- associated with anorexia
- life threatening in both anorexia and severe depression
- eating disorder needs can be all day/ night not just at mealtimes - stress this!
- there is significant harm to physical health associated with anorexia AND bulimia - include under ‘supervision’ too
- associated with psychosis - e.g. some will fear poisoning
- the need to avoid ‘mess’ can prevent people eating properly (e.g. OCD)

◇ I don't think about food - mealtimes don't mean anything to me	◇ Because of the shakes I spill things a lot and need help to clean up afterwards
◇ I feel sick all the time and just don't eat unless someone's there pushing me	◇ I should eat regularly because of my diabetes/ stomach problems/ ulcer
◇ The anxiety affects my stomach so I go without food	◇ Everything has to be perfect or I just lose it and tip it in the bin/ throw it on the floor
◇ I feel so low I just don't eat regularly	◇ I can't wait for people to finish eating - I'm just wanting to take everything away and wash it
◇ When I do eat, it's just junk food - biscuits, chocolate	◇ I think people are trying to poison me so I refuse to eat
◇ There's often nothing in the house if I can't go out and get it	◇ I thought people were taking the food between my mouth and my stomach, so I stabbed myself in the neck to stop them
◇ I starve myself for days as 'control' thing	◇ I have to be encouraged to eat regularly and healthily
◇ I just stop eating when I go down	
◇ I have anorexia	
◇ I have bulimia - I 'binge' on food and then make myself sick	

Medical treatment

Difficulties can be associated with:

- forgetting/ refusing/ taking too many tablets (accidentally or deliberately)
- ‘depot’ injections can suggest there have been ‘compliance’ issues in the past either because of being unwilling to take tablets or forgetting to take tablets
- side effects – remembering that side effects can be from non-current treatment (e.g. ‘extra pyramidal’ side effects from anti-psychotic drugs can last after treatment stops/ memory loss from ECT)
- people self-medicating with alcohol/ drugs
- difficulty remembering appointments/ groups etc
- getting to/ from appointments and being able to participate/ communicate when there
- fears associated with doctors can stop people attending
- many who self-harm won't seek treatment because of feelings of guilt/ fear of others' reaction
- some will try to hide their symptoms, deny being ill or reject the ‘sickness’ label

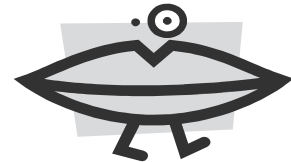


<ul style="list-style-type: none"> ◇ I forget to take my medication ◇ I won't take my medication ◇ I get depot injections ◇ I can get violent ◇ I forget how many tablets I've taken ◇ My difficulties with getting out/ needle phobia/ problems with waiting rooms means I won't go to the doctor/ dentist/ hospital ◇ When I get in there I feel so flustered that I can't say what I want to 	<ul style="list-style-type: none"> ◇ I don't believe that I am ill ◇ I forget/ sleep through appointments ◇ The side - effects of my medication make me drowsy/ stiff/ unable to keep still/ speak oddly/ twitch/ shake a lot ◇ I am visited by/ go and see a CPN/ Social Worker/ Housing Support Worker/ Occupational Therapist/ Counsellor/ Psychologist/ Psychiatrist/ Volunteers ◇ I sometimes won't go/ won't let them in
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Communicating

There's controversial and contradictory caselaw here - I include people's difficulties anyway!

- 'Voices' can be very disruptive and distracting
- Paranoia may get in the way of talking to or being open with people
- People may communicate 'inappropriately'
- Anxiety can make it hard to concentrate/ easy to forget things
- Depression can be so all consuming that communication almost stops
- People may try to hide what's happening for them - can't ask for help
- There may be difficulties with paperwork/ anxiety or paranoia about phones...



DWP decision makers are told that where someone with professional knowledge of the claimant's condition helps to complete the form (e.g. nurse, counsellor, social worker, support worker) this can be a good indication that the information on it is correct... so if you have helped, it might well help to say so. There are no questions on the form about how many days a week/ how often/ for how long - include the information anyway.

<ul style="list-style-type: none"> ◇ I don't trust people ◇ I am frightened of talking to (some) people ◇ I am so anxious I can't concentrate on what they're saying ◇ I have trouble taking in what they're saying ◇ I don't seem able to say what I want to say ◇ I end up agreeing with people - I just tell them what I think they want to hear ◇ I end up in tears when people get impatient ◇ I cannot ask for help during my panic attacks/ when the voices are frightening ◇ I answer the voices - other people think I am saying things to them ◇ Sometimes I shout at the voices ◇ I get mixed up between what someone has really said and what's in my own head ◇ I get very angry with people and end up being verbally aggressive/ violent 	<ul style="list-style-type: none"> ◇ I forget things I've been told - you can't ask people to write it down all the time ◇ I see people's faces changing as I talk to them and stop listening ◇ I feel I communicate with people through their eyes, talk to their souls that way. What they say isn't important; I see the truth ◇ The television and newspapers give me messages ◇ I won't answer the door or the telephone ◇ I forget messages I've been given ◇ I panic as soon as I see a brown envelope ◇ I can't handle forms or official letters - I have to have help ◇ I hide/ don't open my post ◇ I have to have someone with me for company/ reassurance/ to help me understand/ be understood
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Hobbies, interests, social or religious activities...

The space allocated to this area is really very small!

That the questions are there in the first place is down to the landmark 1998 Fairey Halliday ruling, which officially recognised that people with long term illnesses/ disabilities **are** entitled to have hobbies and a social life!

This had MASSIVE implications for people with mental health problems, as in theory, help needed to participate in these now counts towards 'care' needs.

I'd suggest enclosing a separate sheet if you don't have the space to tell the DWP about your hobbies/ social life/ other activities in six lines.

There's potentially a whole batch of caselaw waiting to emerge on how often someone might reasonably need social contact/ leisure activities etc. But on the whole, people with mental health problems should fare better than most, given that it can quite logically be argued that that very

contact is necessary for beneficial health reasons and that lack of it could exacerbate problems.

You do NOT need to tell the DWP again about all the things you've already described in Section 2 - this bit is asking about social activities, hobbies, seeing your family/ friends etc.

They're more likely to accept an hour or three a day to go to the library, meet friends, go to evening classes, groups, etc. than seventy two hours for a weekend's skiing course!

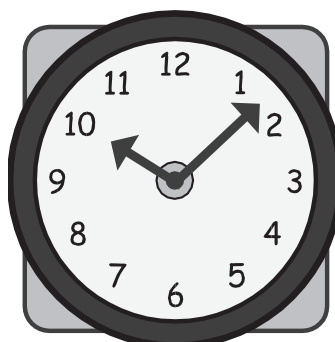


At Home	When I go Out
<ul style="list-style-type: none"> ◇ I like to knit - it helps me relax - but lose concentration and can't follow a pattern without help. 	<ul style="list-style-type: none"> ◇ I play golf but when I was on a 'high' once I decided the bunkers were in the wrong place. I borrowed a mini JCB and started to re-design the course. Now they won't allow me at the club unless I have company.
<ul style="list-style-type: none"> ◇ I lose patience and need to be encouraged to stick with the jigsaw. I see the pieces as a metaphor for my life. 	<ul style="list-style-type: none"> ◇ I like going for country walks but my anxiety and panic get in the way if I try to go alone. I don't feel safe.
<ul style="list-style-type: none"> ◇ I like carpentry but am not safe with some of the tools unless I am being prompted. 	<ul style="list-style-type: none"> ◇ I love taking my grandchildren out for the day but can't always concentrate to make sure they are safe.
<ul style="list-style-type: none"> ◇ I customise bikes. The voices distract me from concentrating on the welding. I need help to do it safely. 	<ul style="list-style-type: none"> ◇ I enjoy going to the library but find the choice of books overwhelming. The librarian knows what I like and makes suggestions.
<ul style="list-style-type: none"> ◇ I love playing my guitar but the neighbours get angry. I need reminding not to turn my amplifier up to eleven. 	<ul style="list-style-type: none"> ◇ I need help and support to enable me to cope with the anxiety I feel when attending chapel - I dread having to leave and making a scene.
<ul style="list-style-type: none"> ◇ I use the internet a lot to chat with people. I need to be supervised/ encouraged not to give out personal information/ form unsuitable relationships. I am vulnerable. 	<ul style="list-style-type: none"> ◇ I am interested in the occult. My nurse says I should have company when I go for readings, to help me sort stuff out.
<ul style="list-style-type: none"> ◇ I love literature but now find I cannot concentrate to read myself. I find being read to very relaxing. 	
<ul style="list-style-type: none"> ◇ I need help to enable me to cook for friends/ deal with entertaining 	

Someone keeping an eye on you (supervision) during the day

What you're trying to show here is why you need someone keeping an eye - or ear - open for you most of the day... There must be some element of risk involved.

- ☞ The question asking 'how long can you be safely left for at a time?' almost invites you to disqualify yourself. You do NOT need someone watching you continuously to qualify under the supervision route, but, for the daytime, you need to persuade them that your need is continual. If your needs are unpredictable, so that they could arise at any time throughout the day just write this in where they ask for a number of minutes.
- ☞ Even though there are separate pages for daytime and night time supervision needs, not much space is left on either DLA or AA forms for the details you may need to include here - add pages if needs be, but staple them on!
- ☞ The tick-box prompts are fairly limited and, frankly, rather clinical and confusing. As a nurse colleague observed 'if you're unaware of common danger you're by definition not aware that you're unaware of common danger'. As well as ticking any of them that apply, you can use the list of ideas on the following page to give a fuller picture and/ or photocopy and complete the 'keeping everyone safe' supplementary page within the chapter on Attendance Allowance.
- ☞ You'll need to include any difficulties you have because of dizziness, blackouts, fits or seizures on this page - they've disappeared from the form as a section in their own right.
- ☞ Don't assume that because you detail something under daytime here you needn't mention it again later if it also applies at night.
- ☞ Likewise if anything can be said to apply to attention AND supervision, repeat it!
- ☞ If you don't realise you're becoming unwell when it is happening, or try to hide it, it's worth saying so in this section
- ☞ Make the connections for the DWP - e.g. 'When I am at my worst I think I can do lots of things that could be dangerous for me. It feels like nothing can harm me. Most of the time my medication prevents this, but when I get worse I don't realise it. I stop believing I am ill and stop taking tablets. I get much worse very quickly then.'
- ☞ Remember to explain how any 'dangers' have a knock on effect on other illnesses/ conditions and detail any past mishaps - e.g. 'when there was a fire because I'd left something on the stove I got a panic attack and asthma and was so breathless that I couldn't speak when I tried to call for help'
- ☞ Questions about self-harm, self-neglect and aggression can be especially painful to answer. You may decide you want to ask a friend to help you or get help from someone else to fill in the form. If you're helping someone else with a form, try to be sensitive to what you're actually asking them to talk about, and recognise that they may feel embarrassed or upset by sharing that information. Open questions such as 'have there ever been times... when things are at their worst for you...?' can help someone to give an affirmative answer. Also see the next page.
- ☞ When answering, try to think about the four-part test for supervision mentioned earlier in this chapter. It's not suggested that you phrase the additional information you give to specifically address these points, but if you can include any information which will aid the adjudication officer in reaching the right decision, all well and good!



Decision makers will sometimes come out with really crass things dismissing people's supervision needs - e.g. dismissing the cutting associated with self harm as 'superficial', or implying that suicide attempts were not 'serious' because they didn't succeed.

Where you feel that a decision maker (or a presenting officer at a tribunal) has been particularly insensitive, please consider making a complaint to the DWP, along with a request that that person be sent on mental health awareness training.

In the meantime it might be helpful for you to know:

Self Harm

- even superficial cutting carries a risk of infection
- a knife or razor blade slipping during 'superficial' cutting can lead to unintentional more serious injury/ tendon damage etc.
- if someone uses a knife or razor to self harm they could be in danger of picking up - or passing on - blood borne diseases
- although deliberate harm may carry no suicidal intent in itself, statistical evidence shows that people who repeatedly self harm are at a significantly higher risk of going on to commit suicide eventually.

Suicide

- It is a myth that people who talk about committing suicide don't do it. In fact over a third of people who kill themselves are known to have talked about doing just that.
- People who have also thought about *how* they would take their own life are statistically more at risk.
- Unsuccessful previous attempts at suicide don't mean that the intention wasn't 'genuine' - in fact statistics show that over a tenth of people who try for a first time will eventually succeed in taking their own lives.
- Statistically, repeated suicide attempts make it even more likely that that person will eventually succeed.
- Something that looks like a 'cry for help' to an outsider can still have had serious intention behind it. Most lay people would have no idea what a lethal dose of certain drugs was.
- A 'cry for help' can still be very dangerous. There is caselaw which supports this and which decision makers/ tribunals may need reminding about. Its reference if you ever need to use it is CSA/68/89
- Caselaw also dismisses the argument that no amount of supervision could prevent someone who was really determined to take their life from doing so. What should be considered instead is whether supervision could mean a 'real *reduction* in risk' R(A) 3/92



Someone keeping an eye on you

<ul style="list-style-type: none"> ◇ I have tried killing myself (give details if you feel able to) ◇ I have planned how I am going to kill myself ◇ I was in intensive care for... ◇ They put me on a drip ◇ I ended up in hospital because someone found me... ◇ I don't think I really wanted to die, but I did want things to stop... ◇ I cut myself with razor blades/ knives etc. ◇ I burn myself deliberately - it helps when things feel too much ◇ I don't feel able to go to the doctor when I've done this - they don't understand ◇ I've ended up stitching up my own cuts ◇ I have bad scars ◇ I don't look after myself ◇ I don't eat enough (explain with examples as for 'mealtimes') ◇ This is dangerous because of my diabetes ◇ I stop eating/ refuse to eat ◇ I have difficulties looking after my children without help ◇ I get very angry and trash the place - I have hurt myself by punching walls/ doors (detail if possible) ◇ I get very angry and hurt others (physically or emotionally? Explain as much as you feel able to) ◇ When I lose it I don't know what I'm doing/ can't remember what I've done ◇ I do daft things - like climb onto the roof of a building ◇ I thought I could fly... ◇ I walked out into the road because I was convinced I could stop the traffic ◇ I spend money I just haven't got ◇ I give my money away to other people ◇ People take advantage ◇ I sometimes go off to big towns - I've spent weeks/ months living on the streets 	<ul style="list-style-type: none"> ◇ I end up with people I shouldn't go with - people say I am very vulnerable ◇ I am convinced that people want to harm me so I end up having a go at them first ◇ People have a go at me because of the way I behave/ look ◇ I have been on probation/ in prison ◇ I was taken to a 'place of safety' when... ◇ I have been admitted to hospital (under compulsory section?) ◇ I have had many stays in hospital ◇ The voices make it hard to concentrate on what I'm doing ◇ The voices I hear tell me to harm myself ◇ The voices I hear tell me to harm others ◇ I thought I was Jesus/ a Saint/ the Devil and must spread the word/ warn others/ etc. This can make people scared and angry because they don't understand. ◇ The panic/ anxiety bring on my asthma/ angina... ◇ I get in such a state I cannot call for help ◇ I can faint and fall and hurt myself when I get the panic attacks ◇ I stop taking my tablets without warning ◇ When this happens I get ill very quickly ◇ I can get very unwell very quickly ◇ People can't tell when I am becoming unwell unless they are with me all the time ◇ I can't tell when I'm getting more unwell ◇ Very little things can trigger it off ◇ The side effects of the drugs I have to take can be dangerous - I have to have lots of blood tests and someone has to keep an eye on me for warning signs ◇ When I do become unwell the things I do are very dangerous for me/ for other people ◇ The only way to make sure I am safe is for someone to be there all the time ◇ When I've tried to take my life, it hasn't been when I was at my most down ◇ People didn't expect it - it's not predictable ◇ Someone has to be with me or I'll just start cutting myself/ making myself sick when they leave
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Preparing and cooking a main meal (DLA only)

This is an important route to the lower rate Care Component of DLA. It looks at whether you can safely co-ordinate all the physical and mental processes involved in cooking a main meal - not your actual cooking skills! The 'main meal' in question is defined by caselaw as a labour intensive, main daily meal for one person - neither a celebration meal nor a snack. It should be considered in the context of preparation on/in a conventional cooker, not re-heating something in the microwave.

- ◇ I feel so low I just can't make myself do it
- ◇ I can't plan what to eat, let alone cook
- ◇ I just do 'convenience' things
- ◇ My concentration is bad - I can't co-ordinate things
- ◇ I don't make sure that things are properly cooked
- ◇ I forget I've got things on
- ◇ I let things burn/ there have been fires/ I burn myself
- ◇ I try cooking in the middle of the night and end up leaving things on



NB - if any of the last four apply, you should also include them under supervision needs on the previous page.

People will sometimes attempt to cook but will not check that food is fresh, or that it is cooked thoroughly. There is, apparently, a higher incidence of food poisoning and gastrointestinal upsets amongst people with mental health problems. And if your stomach is out of sorts you won't be absorbing your medication properly. And if you're not absorbing your medication properly your mental health symptoms may get worse... This is not just a difficulty with cooking! It should also be mentioned on the pages relating to medication, eating - and even, potentially, help with your toilet needs.

The missing pages: Mental Health

For some bizarre reason, the page relating to Mental Health was dropped in 2007. I suspect that many more people now pick up a set of forms, flick through them and then bin them assuming they're just about physical health. The prompts on the 'old' page were fairly helpful and have NOT been incorporated in full into the new forms. And although you can argue that *most* needs could be included elsewhere, this space was still useful if someone wanted to include background information, or wanted to say something more about their mental health

Dizzy spells, blackouts, fits, seizures... have also disappeared from the forms, their only mention being as 'an example' on the supervision pages! Although perhaps not immediately obvious, panic attacks can cause dizziness/ feelings of faintness, psychotic symptoms can cause 'loss of awareness or concentration' - as can anxiety. Psychosis also obviously causes 'altered states of consciousness or awareness'. Uncontrollable anger has been likened to an active form of 'blacking out'. Try to include anything that applies on the supervision pages.

◇ The panic attacks make it difficult to breathe and I feel very giddy	◇ I need help to get/ take/ use my tablets/ inhaler
◇ I have to find somewhere to sit down/ grab hold of something	◇ I need encouragement to do my breathing exercises
◇ At times I have fainted	◇ I get in such a state I can't call for help
◇ I have hurt myself when I fainted	◇ I get in such a state I ring 999
◇ The panic can trigger my asthma/ angina	◇ I don't get any warning that the panic's coming - anything can set it off

The 'night time' pages

It's very sad that the pages relating to night time needs only address difficulties to do with 'being in bed', getting to the toilet, taking medication and being a/t risk!

The law says that help with ANY 'bodily functions' counts just as much at night as during the day.

When you are in bed at night

◇ I need lots of encouragement, reassurance and calming before I can get off to sleep	◇ As above... because of my PTSD
◇ I need lots of encouragement, reassurance and calming to a state where I can get back to sleep when woken by my nightmares	◇ As above... because of my voices, paranoid thoughts etc
◇ As above... when the panic attacks happen	◇ The voices seem more 'there' at night
	◇ Everything feels worse at night
	◇ The voices are worse at night

Toilet needs at night

◇ I'm terrified of the darkness outside my room, so if I need to go to the toilet someone has to get up and come with me	that I am not woken by my bladder being full. I sometimes wet the bed at night
◇ Because of the (sleeping) tablets I'm drowsy at night. If I get up I sometimes stumble/ fall	◇ Going to the toilet upsets me/ makes me feel dirty so I limit the amount of liquid I drink to a bare minimum
◇ When I'm really anxious/ panicky I lose control of my bladder/ bowels	◇ After I've been to the toilet I feel I have to wash and wash afterwards - I sometimes can't stop without reassurance. Sometimes I feel the need to get up and start again. I need encouragement not to do this.
◇ I get so upset I need help to clean myself up afterwards	◇ I have been so depressed - so terribly low - that I have stayed in bed and dirtied myself instead of getting up to use the toilet
◇ The anxiety makes my Irritable Bowel Syndrome worse. This means that...	
◇ I get bouts of vomiting because of anxiety	
◇ I sleep so soundly because of the tablets	

Medication/ Medical Treatment at night

◇ Because of the (sleeping) tablets I'm drowsy at night. If I get up I sometimes stumble/ fall	◇ Sometimes I find it hard to distinguish between a panic attack and my asthma. Sometimes I have to be calmed to the state where I can use my asthma pump.
◇ I find it hard to remember whether I've taken tablets or not.	◇ I use alcohol/ non prescription drugs to help me sleep/ block out my fears/ voices etc. I need to be encouraged not to.
◇ I have accidentally overdosed.	
◇ I need to be encouraged not to take too many tablets	
◇ Sometimes I find it hard to distinguish between panic and angina. My partner helps me to work it out and encourages me to use my breathing exercises or angina spray depending on which is needed	



Other night time care needs the form doesn't ask about

<p>Moving around my home:</p> <ul style="list-style-type: none"> ◇ I need lots of encouragement to stay in bed and not to move around my home at night. ◇ Because of my problems I am up and awake for hours unless someone encourages me to go (back) to bed ◇ I need encouragement to do this and try to establish a more usual sleeping pattern ◇ My OCD means that my checking rituals can go on long into the night ◇ I have an order in which I have to do things. If it goes wrong I have to start again. I need encouragement and reassurance to enable me to leave it and go to bed ◇ I feel paranoid about the neighbours and will spend hours watching their house in the dark unless encouraged and reassured so I can go to bed and sleep <p>Washing/ bathing etc:</p> <ul style="list-style-type: none"> ◇ My feelings of dirtiness can be overwhelming at night. Sometimes I feel compelled to get up and have a good scrub ◇ My OCD means I have to wash/ bath/ shower repeatedly. It has been as late as 3.00 before I've got to bed. ◇ My skin is raw because of repeated washing ◇ I am so low that I sometimes dirty the bed. I need encouragement and sometimes physical help to wash/ clean myself ◇ When I have self - medicated with alcohol I often wet the bed. I need encouragement to wash/ clean myself afterwards. <p>Eating and drinking:</p> <ul style="list-style-type: none"> ◇ I am so ashamed of my bullimia that I will binge eat at night ◇ I will then make myself vomit ◇ When the anxiety is bad I get up in the middle of the night and use alcohol to try 	<p>to help me sleep</p> <ul style="list-style-type: none"> ◇ I comfort-eat in secret. My doctor says I am morbidly obese. <p>Dressing/ undressing:</p> <ul style="list-style-type: none"> ◇ Because of my dementia I get up at night. It does not occur to me to dress warmly ◇ Before now I have been found trying to get out of the house without clothes on ◇ I wander around the house without clothes and with the curtains open. The police were called once. <p>Communicating:</p> <ul style="list-style-type: none"> ◇ I telephone people at bizarre hours, looking for reassurance. I need someone to be there in the house encouraging me not to do this. ◇ Because of my panic/ paranoid thoughts I have called the emergency services for very trivial things ◇ Because of my dementia I think there are thieves coming in I the night. I have called the police many times. ◇ Because I am so anxious I do not like to bother people at night. Once when I had chest pains at night I waited until it was nine o'clock to phone the GP. It turned out I had had a small heart attack. ◇ I stay up chatting on the internet all night and then sleep all day. I need pushing to follow more usual patterns. <p>Hobbies/ social activities etc:</p> <ul style="list-style-type: none"> ◇ I love astronomy but am terrified of the dark. I need company to enable me to enjoy my hobby ◇ I want to go to clubs to meet girls like other men my age do, but couldn't go alone ◇ I need help to be able to have sex ◇ I need reminding to use contraception
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*Basically don't be afraid to include ANY information relating to the 'attention' needs you have at night. This may mean having to use up a lot of the 'anything else you want to tell us' space on pages 31 and 37 of the forms, or adding extra sheets of paper. Encouragement and reminding **not** to do something counts just as much as encouragement to do something does - as long as it is 'in connection with bodily functions'.*



Someone to watch over you

This is the night-time equivalent of the ‘someone keeping an eye on you’ page earlier in the form - **so read back over that section of this chapter and the prompts offered there. Remember to mention anything that might apply at night.**



The test for night time supervision is similar to the daytime one, but the supervision doesn't have to be continual at night - instead it needs to be ‘prolonged or repeated’. Caselaw says this means for 20 minutes or more, or more than once. There must still be risk involved.

◇ I get up and wander about the house - I've done things like leave the fire on...	◇ I need to be watched and encouraged not to drink because of my medication
◇ Because of the (sleeping) tablets I'm drowsy at night. If I get up I sometimes stumble/ fall	◇ at times I am sexually disinhibited
◇ I find it hard to remember whether I've taken tablets or not	◇ I might/ have caught VD/ AIDS/ hepatitis
◇ I cut/ hurt myself during the night	◇ I might/ have had unwanted pregnancies
◇ I think about killing myself	◇ I got/ might get someone pregnant
◇ I have tried to kill myself...	◇ I dress provocatively and go out to pubs
◇ I drink at night to try to help myself sleep. I have drifted off with a cigarette still burning in my hand...	◇ I get falling down drunk
◇ I have wandered off at night	◇ My alcoholism is damaging my health
◇ I met some not very nice people	◇ I stay on the internet at night. I give out personal information to people.
◇ I am very vulnerable	◇ A couple of them have actually turned up at my parent's house expecting sex.
◇ I want people I meet socially to like me - I am easy to influence	◇ When I'm high I go on eBay all night and bid for all the things I want
◇ I get falling down drunk	◇ I bought £6000 of things using my wife's credit card
	◇ I make myself vomit into a plastic bag at night. The enamel is wearing off my teeth

Getting there - getting the statement completed/ other supporting evidence

The ‘statement from someone who knows you’ can make a big difference to the success or otherwise of a claim - and it's the familiar rule of ‘my credibility/qualification's bigger than yours’ that applies here. The statement doesn't HAVE to be completed by a medical person, but the more impressive sounding their qualifications, the more likely the DWP are to take their word for it! Not much space is offered - all well and good if people are happy to do a more detailed letter which you can staple in.

If the person who knows most about how you are says they don't know enough about how DLA works to be able to help then you could always show them this book - including the sample letter that follows - or ask them to put in writing that they have read your form and that they can confirm, in their opinion, that it is an accurate picture of your difficulties.

Sadly, increasing numbers of GP practices are choosing to charge people for supporting letters to do with their benefits. There's not a lot you can do about this unfortunately - GPs are under no obligation to provide you with supporting letters for free. Three (and probably four) cheers then for the GPs and other providers of support out there who continue to spend time - free of charge - supporting people's health by actively supporting entitlement.

Supporting letters can be invaluable, whether to accompany initial claims or as a back-up when wrong decisions are made. The letters which are most useful are the ones that actually address the issues that the DWP consider when looking at DLA. Medical-speak also seems to impress Decision Makers!

Dear Sir/Madam,

I have been asked to write to you in connection with Mr D. Pressed's claim for Disability Living Allowance. I have been working with Mr Pressed fornow in my capacity as at.....

Mr Pressed suffers from chronic lowness of mood and anxiety which impact considerably on his day-to-day life and personal care. Up until six months ago he lived alone and was obviously suffering from the effects of long term self neglect - he often arrived for counselling late, unwashed and unshaven, was visibly losing weight and was very withdrawn. He also missed many appointments because of anxiety about going out alone and was unable to participate in the many activities organised by Social Services' Day Care Team because of problems with socialising.

More recently Mr Pressed's outward condition has changed remarkably in that he is now receiving the daily and repeated support, prompting, encouragement and reminding he doubtlessly requires in terms of personal care from his new partner. I understand from Mr Pressed that she prompts and encourages him to get up, wash, dress, change his clothes, eat regularly and be productively active within the home. She also supervises his medication and helps him to use his asthma inhaler. In addition she is able to provide the daily support and reassurance Mr Pressed needs to get out and to socialise.

Please contact me if I can be of further assistance in this matter....

Dear Sir/ Madam,

I write concerning Mr W of whom I see for counselling at Hospital. He was referred to the Hospital by his Consultant Psychiatrist.

Mr W's mental health problems came to a head last year after his wife was diagnosed as suffering from Multiple Sclerosis, although this was just one of a number of extremely stressful life events with which he was trying to cope at the time. These included a close family bereavement and change of job. Although one would obviously expect considerable lowness of mood to result from such news, Mr W has gone on to develop mental health problems and has been forced to take voluntary redundancy on health grounds as a result.

His confidence, self-motivation and concentration have all been severely affected. He is unable to escape the constant anxiety he experiences unless being actively engaged in some other activity, which is possible only through sustained prompting from somebody else. Even then, he has problems with taking in and processing the information being conveyed to him and will often find his mind wandering, making communication a lengthy and at times frustrating process.

He also experiences difficulties with concentrating to read, watch TV etc. and indeed is unable to be productively active when left alone because of the intrusive and all-consuming nature of his own thought processes. His lowness of mood and resultant lack of ability to motivate himself interfere with the daily processes of getting up, dressing, washing/shaving etc. and he will often go back to bed during the day unless prompted to do otherwise. He is frequently tearful. His appetite is poor and he finds it hard to motivate himself to eat regularly, let alone cook a main meal.

Mr W also experiences considerable difficulties outside his home, especially if trying to cope with the extra demands made on his concentration by being in unfamiliar settings, or if feeling at all 'enclosed', even when out in the street. The same problem also means that although aware of common dangers, sustaining the concentration to deal with them safely is beyond him, resulting in several domestic mishaps and some 'near misses' both at home and when outside.

To conclude then, Mr W is considerably disabled by his symptoms whether at home or outdoors. I hope this information will be of use to you; please do not hesitate to contact me if I can be of any assistance.

Yours faithfully,

Dear Sir/Madam,

Re. Mrs D

Mrs D has been a patient of mine for some years now and has a diagnosis of schizophrenia. She has been hospitalised for a prolonged period in the past because of her illness and is now visited regularly by a Community Psychiatric Nurse. She takes Stelazine and Procycladine.

When psychotic, she experiences both visual and auditory hallucinations and exhibits both bizarre behaviour and thoughts of self harm, putting herself at risk. She also experiences paranoid ideas and has, in the past, refused food over a period of weeks, believing it to be poisoned.

Between bouts of more acute illness, Mrs D experiences considerable anxiety and lowness of mood which mean that she needs frequent and repeated prompting and encouragement in connection with her mobility, personal care, communication and social functioning.

If left alone she experiences extreme anxiety, impinging on her capacity for personal care, leading to panic attacks and resulting in extreme levels of non-productive activity. At other times she will experience lowness of mood, and will either take to bed because she feels 'safer' there or sit in darkness. Her anxiety keeps her awake for long periods at night, leaving her extremely tired the next day. She therefore requires prompting and encouragement to get up, wash and dress, eat regularly and be meaningfully active within her home throughout the day. She would also benefit from encouragement to go to bed and reassurance to enable her to reach a mental state where she will be able to settle to sleep.

In terms of day-to-day mobility, communication and social functioning, her anxiety means that she suffers from feelings of fear and distrust as well as panic attacks when in unfamiliar settings and situations. She therefore requires encouragement, prompting and reassurance on a daily basis as well as guidance and supervision to obviate risk when more acutely ill.

I hope that this information will be helpful to you when making your decision.

Yours faithfully,

Dear Sir/Madam,

I write in support of Ms C' application for Attendance Allowance. As her keyworker, I see Ms C regularly and have known her for three years.

Ms C has been diagnosed as suffering from Manic Depressive Psychosis and has required several admissions to hospital in recent years, sometimes under section of the Mental Health Act. Her condition changes very rapidly and when becoming more unwell she has no insight into her illness, stops taking her medication etc. etc.

Ms C neglects her personal care both during the manic and depressive phases of her illness. When depressed she will take to her bed throughout the day, not able to wash, dress, take her medication, eat etc. without prolonged and repeated prompting, encouragement etc. from others. She has also, at times like this, overdosed.

When in the manic stage of her illness she becomes consumed by grandiose ideas and schemes and spent £5,000 - representing her life savings and more - during her last bout of illness. When in this stage of her illness, Ms C talks compulsively, can become aggressive in her reactions to others and does not stop to think of day to day necessities such as eating, sleeping, taking medication, dealing with personal cleanliness etc. unless repeatedly prompted to do so. Her aggression is not always confined to reaction either - she will at times actually telephone or go to call on and confront people she feels have upset her.

Additionally, when in the manic phase of her illness she does not go to bed and during her last bout of illness fell asleep whilst in a public park because of staying up for nights on end. She was also quite unrealistically planning on travelling abroad, which would have been disastrous for her given her heart condition and general ill health. Her concentration and awareness of common dangers are also affected because she becomes preoccupied with one task to the exclusion of all else. She can therefore put herself and others at risk by leaving pans on the stove without remembering, leaving the door open, crossing roads without looking for oncoming traffic etc. Indeed during one episode she felt she was able to control the traffic through her brain.

Eventually, then, she becomes so unwell that she has to be hospitalised under section. This process has, in the past, required the intervention of the emergency services because of her behaviour.

Her medication is only partially successful at controlling the manic phases of her illness and does not alleviate the depression. To hope to achieve any reasonably stability in the community, Ms C will continue to require both much support and supervision from her family and an unusually high level of support from Community Mental Health Services.

I hope that this information will be helpful to you in reaching a decision, but please do not hesitate to contact me if you require further details.

Yours ,

DLA, AA and (possibly) being assessed by a doctor...

After your forms are sent off, you should get a standard letter back acknowledging your claim and outlining what happens next. Somewhere in the letter will be a statement saying that they may send a doctor to see you. ask you to attend a medical examination.

The doctors referred to here are usually called 'EMPs' - examining medical practitioners -by advisors (amongst other things!) and are from the same stable as the doctors who carry out Incapacity/ ESA Assessments - i.e. Atos Origin doctors - see the chapter on Sickness Route Benefits. Although it is less likely that a doctor will be asked to visit you if your problems are 'only' mental health ones, it can still happen. The chances of being visited by a doctor if you also have some sort of physical disability seem much higher.

You do not HAVE to agree to see a doctor, although be aware that refusal to do so may mean your claim being turned down unless you can show 'good cause'. So if seeing a strange doctor would be distressing for you, try to get some sort of supporting letter to back this up - ideally from a doctor or consultant.

You should be given reasonable notice of when the doctor will call - certainly turning up unannounced on the doorstep is *not* acceptable. This is particularly important of course if you would like someone to be there for company for you when the doctor calls - which is a very reasonable request. If you have a CPN or Social Worker ask if they might be willing to be with you; otherwise ask a friend.

You can also request a same gender doctor and/ or an interpreter - although when medical services were run by SEMA they were criticised for their inability to provide these in all cases.

In an ideal world, the doctor would have plenty of time, and would consider both your physical and mental health carefully. What sometimes seems to happen though is that examinations/ interviews are too brief, mental health issues are sometimes missed or ignored and/ or the doctors seem to jump to black and white conclusions about what you can and can't do, instead of

listening to you describe your difficulties, pain, how slow it is for you to do things etc.

It's not easy to know what to do about all this. It's all very well for me to say 'insist that they listen and write down everything that you feel is relevant', but I also know that the power imbalances involved - along with the attitude of some doctors - makes this very difficult in reality. It may help then to have jotted down a list of the problems you have BEFORE you see the doctor or copy any supporting letters you have - and then hand them to him/ her on the day smiling sweetly and saying 'I wondered if these might help'....

Whether you do it verbally or by writing something down though, it's very important that you do what you can to get the information over to them in some way, shape or form, because they have no prior knowledge of your case, no idea of any existing awards and no sight of your claim form/ supporting letters that went with it.

The form the doctor completes has a section where s/he records what YOU say, and another for their own opinion. Unfortunately the two don't always seem to be about the same person! You will be asked to read and sign the piece based on YOUR comments - certainly don't sign anything you feel is wrong or less than complete.

It may also help if you ask the doctor how you can go about obtaining a full copy of his/ her report once it is finished - and even what you can do about it if you do not agree with it. It won't do any harm to remind them that what they say about you - a real person, not just a bit of paperwork - will come back to you and that you could, potentially, complain. There is, of course, a fine line between showing an interest in your rights and putting their backs up..... you will have to judge!



As with sickness route benefits interviews, be aware that you will be under observation from the moment they set eyes on you, and, if visited at home, the way that your house - and even your garden - looks, along with any information you offer may well be used to form conclusions about you and your illness and/ or disability.

Also as with sickness route benefits medical examinations/ interviews, you have a right to be treated courteously and with respect - see the chapter about Sickness Route benefits regarding complaints etc. It's certainly worth jotting down as much as you can remember about the interview as soon as you can - how long it lasted, any questions you were uncomfortable about, places where s/he didn't seem to listen, anything outrageous/ upsetting they said.

Don't, then, put up with unacceptable behaviour, but don't read too much into their manner either! Some doctors can seem disinterested but still come up with decent reports, whereas even the most courteous seem capable of missing vital points - and at the end of the day what's important is what is said in their report.

It's doubly important because of the weight the DWP put on EMP's reports. You might quite reasonably assume that if the DWP have the evidence in your own claim pack and a letter from your own doctor, who knows you well, to back it up, they will give them more weight than something said by a stranger who has only met you once.

Unfortunately some DWP decision makers seem to cling to the reports of EMPs like holy grails, saying how much 'more independent' they are..... and therefore preferring them over any other evidence.



Of course Welfare Rights Workers get to hear about the worst examples of decision making and EMP visits because they get asked to help when things go wrong with people's claims. Not all Decision Makers are bad, just as not all EMPs are bad - so don't panic if you do get a letter saying they'd like you to see one. But it is certainly worth arranging company if you can - even if it's just for some moral support - and making some notes afterwards.

The Decision

Very soon after your form goes off, you SHOULD receive a written acknowledgement. If you don't, get in touch with them. Some weeks later will follow a decision letter. It may, or may not be good news - but whatever the case, it's likely to cause some confusion and possibly some distress. That's because the letter simply parrots back the law at you in very cold terms, without giving any of the current interpretations of the regulations as developed through caselaw.

So, for example, it might well say that you have been awarded benefit because 'you are so severely disabled that you require frequent attention throughout the day in connection with bodily functions' when in fact you've been awarded benefit because you need prompting and encouragement to do things...

The decision letter will also tell you what information the DWP have used in making their decision. Your claim form will always be one of their sources, along with the EMP's report if you saw one of their doctors. But you might also find a report listed that you had no idea about - often from your GP, but sometimes from a Consultant, CPN or Social Worker. These reports - known as 'factual statements' - are something the DWP pay for, and are not the same as the statement part of the form.

From a mental health perspective, they're usually not good news because many of the questions within them are couched in physical terms. For example your doctor may see questions about your ability to get out of bed, wash and dress, move around your home etc. and answer that you can do these things without help (thinking in physical terms) without considering any ENCOURAGEMENT you need to do them. The questions that are more *obviously* mental health related are, predictably, all about risk.

Additionally the choices given are all very black and white - you can either manage alone, or can only manage with help - no grey areas here! It can be very easy then for a seemingly unsupportive report to be written without the author actually realising they are doing it!

YOU HAVE A RIGHT TO ASK FOR COPIES OF ANY REPORT THAT HAS BEEN WRITTEN ABOUT YOU. If you are disappointed with the result of your application, then it is certainly worth getting copies of any reports, as they may help in seeing why you were not as successful as you hoped. You can also ask for the full written decision which should give more detail than the initial letter. If you still feel the result is not the correct one, see the chapter on Challenging Decisions for your options.

Awards of DLA and AA are sometimes made for a fixed term period - with the understanding that you can apply again at the end of this time - or they may be left open ended. This does not mean that your benefit will never be reviewed!

In fact it's been decided that lifetime awards should no longer be made - the reason given by the DLA Advisory Board being that with medical science advancing all the time, even conditions for which there is currently no effective treatment may one day be treatable!



Getting Paid DLA/ AA and Claiming Again

First applications for DLA and AA are still *often* made to regional centres (although some local Disability Benefits Centres are closing and their work is being centralised in Blackpool. Basically if in doubt, use the pre-paid envelope which came with the form!) If benefit is awarded, you should receive a giro covering the weeks taken to make the decision from your regional centre. They will also make arrangements with your bank if you are being paid that way. Although the option to be paid by order book is not now given on application forms, you can still be paid by giro if you feel determined or just can't handle an account - get advice.

Three months after the award is made, all your documentation is transferred to the national Disability Benefits Unit in Blackpool (unless it's already there from your initial claim). After this time, they are the people who administer payment and they will be the ones who deal with any repeat claim.

The repeat application form is issued automatically six months before an existing award is due to end. Once you have received it, you will then get reminder after reminder until you return it.

There are arguments for and against completing the form as soon as it arrives. On the one hand it's out of the way and the reminder letters stop. On the other hand, if your award is reduced, then they usually substitute the new amount immediately. What is important is that you allow enough time for the form to go back and for a decision to be made before your current DLA award runs out!

You can request copies of your old forms - and the DBC seem to be getting better, on the whole, at finding them... It can certainly be helpful to remind yourself of what you told them about last time, and will help you to identify any increase or decrease in your needs.

Sometimes you will find that although your needs have not changed your award does. If this happens get advice; bad decisions are made and can be challenged...

Personal Independence Payment - the future of DLA

Since last year's book and our early look at PIP, a lot more detail is emerging...

The case for change

Initially, the Government stated its intent to bring in 'independent' medical assessment for all recipients of DLA, with the aim of cutting a whopping 20% off the budget and reducing the number of recipients by 500,000.

This was, according to Chancellor, George Osborne, to allow the government to '*continue to afford paying this important benefit to those with the greatest needs, while significantly improving incentives to work for others.*'

By December, the agenda had changed again, with a Government Green Paper announcing the replacement of DLA - from 2013 on - with the Personal Independence Payment.

This of course enables the Government not only to make sure that medical assessment becomes the norm but also to fundamentally change the qualifying criteria...

What will PIP look like?

PIP will, like DLA, be:

- non means tested,
- non contributory
- payable whether or not in work.

Just as DLA has a Care Component and a Mobility Component there will be two parts to PIP:

The **Mobility Component** '*awarded on the basis of 'the individual's ability to get around and the*

Daily Living Component '*awarded on the ability to carry out other key activities necessary to be able to participate in daily life (the daily living component).*'

There will be two rates of each Component:

- a '**Standard**' rate for those whose 'mobility activities' or 'daily living activities' are *limited* by their 'physical or mental condition' and
- an '**Enhanced**' rate for those whose 'mobility activities' or 'daily living activities' are *severely limited* by their 'physical or mental condition'.



At first sight then PIP looks like DLA but with two rates of Daily Living as opposed to three rates of Care. But it's not as simple as that...

The activities which they're looking at assessing for PIP are considerably fewer than those counted for DLA.

At the moment they are:

Daily living component

1. Preparing food and drink
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Bathing and grooming
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating
8. Engaging socially
9. Making financial decisions

Mobility component

10. Planning and following a journey
11. Moving around

Each of these activities contains a number of Descriptors, each of which will score points, much as within ESA. The ones currently being proposed along with the associated scoring can be found overleaf.

Within each Component, scoring 8 points will qualify you for the Standard rate of PIP whilst scoring 12 or more points will qualify you for the Enhanced rate.

Daily Living Component

1. Preparing food and drink

- b. Needs to use aid or appliance to either prepare or cook a simple meal 2
- c. Can't cook a simple meal using a cooker but can using a microwave 2
- d. Needs prompting to either prepare or cook a simple meal 2
- e. Needs supervision to either prepare or cook a simple meal 4
- f. Needs assistance to either prepare or cook a simple meal 4
- g. Cannot prepare and cook food and drink at all 8

2. Taking nutrition

- b. Needs either:
 - i. to use an aid /appliance/ therapeutic source to take nutrition
 - ii. needs assistance to cut up food 2
- c. Needs to use a therapeutic source to take nutrition 2
- d. Needs prompting to take nutrition 4
- e. Needs assistance to manage a therapeutic source to take nutrition 6
- f. Needs another person to convey food and drink to their mouth. 10

3. Managing therapy/ monitoring medical condition

- b. Needs supervision, prompting or assistance to manage medication or monitor a health condition. 1
- Needs supervision, prompting or assistance to manage (medically prescribed/ recommended) therapy that takes:
 - c. up to 3.5 hours a week. 2
 - d. between 3.5 and 7 hours a week 4
 - e. between 7 and 14 hours a week 6
 - f. at least 14 hours a week. 8

4. Bathing and grooming

- b. Needs to use aid/appliance to groom 1
- c. Needs prompting to groom 1
- d. Needs assistance to groom 2
- e. Needs supervision/ prompting to bathe 2
- f. Needs to use aid/ appliance to bathe 2
- g. Needs assistance to bathe 4
- h. Cannot bathe and groom at all 8

Standard Rate = 8+ points

Enhanced Rate = 12+ points

within each component

5. Managing toilet needs or incontinence

- b. Needs aid or appliance to manage toilet needs or incontinence 2
- c. Needs prompting with toilet needs 2
- d. Needs assistance to manage ditto 4
- e. Needs assistance to manage incontinence of bladder or bowel 6
- f. Needs assistance to manage incontinence of bladder *and* bowel 8
- g. Cannot manage incontinence at all 8

6. Dressing and undressing

- b. Needs aid/appliance to dress/undress 2
- c. Needs either –
 - i. prompting to dress, undress or determine appropriate circumstances for remaining clothed; or
 - ii. assistance or prompting to select appropriate clothing 2
- Needs assistance to dress or undress:
 - d. lower body. 3
 - e. upper body 4
 - f. Cannot dress or undress at all 8

7. Communicating

- b. Needs to use an aid or appliance other than spectacles or contact lenses to access written information 2
- c. Needs to use an aid or appliance to express or understand verbal communication 2
- d. Needs assistance to access written information 4
- e. Needs communication support to express or understand complex verbal information 4
- f. Needs communication support to express or understand basic verbal information 8
- g. Cannot communicate at all 12

8. Engaging Socially

- b. Needs prompting to engage socially 2
- c. Needs social support to engage socially 4
- d. Cannot engage socially due to such engagement causing either:
 - i. overwhelming psychological distress to the individual; *or*
 - ii. the individual to exhibit uncontrollable episodes of behaviour which would result in a substantial risk of harm to the individual or another person. 8

9. Making financial decisions

- b. Needs prompting to make complex financial decisions 2
- c. Needs prompting to make simple financial decisions 4
- d. Cannot make any financial decisions at all 6

Mobility Component

10. Planning and following a journey

- b. Needs prompting for all journeys to avoid overwhelming psychological distress to the individual 4
- c. Needs either –
 - i. supervision, prompting or a support dog to follow a journey to an unfamiliar destination; or
 - ii. a journey to an unfamiliar destination to have been entirely planned by another person. 8
- d. Cannot follow any journey because it would cause overwhelming psychological distress 10
- e. Needs either –
 - i. supervision, prompting or a support dog to follow a journey to a familiar destination; or
 - ii. a journey to a familiar destination to have been planned entirely by another person. 15

11. Moving Around

- b. Can move at least 50 metres but not more than 200 metres either unaided; or using an aid or appliance, other than a wheelchair or a motorised device 4
- c. Can move up to 50 metres unaided but no further 8
- d. Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device 10
- e. Cannot move up to 50 metres without using a wheelchair propelled by the individual 12
- f. Cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device 15
- g. Cannot either:
 - i. move around at all; *or*
 - ii. transfer unaided from one seated position to another adjacent seated position 15

Descriptor a. in each activity reads Can manage...unaided 0 points. For 11, it reads can move at least 200 m...

DWP Guidance

On top of the points system, the people framing PIP have produced copious ‘Guidance’ about how the new benefit will work. Whilst not binding on Decision Makers, Guidance can be helpful, especially when it reflects principles that are established in case law in other benefits

The single most important point made by the PIP Guidance is that you should only be treated as being able to do something if you can do it “reliably, repeatedly, safely and in a timely fashion” - e.g. although you might be able to do something once on a good day, could you do it repeatedly or reliably? Does it take you a lot longer to do things because of concentration difficulties or checking routines?

This of course is likely to be the sort of subtlety that medical assessment will often fail to pick up on - and which will need to be stressed time and time again - in applications, supporting evidence and Appeals.

Other elements of the Guidance seek to define things like the differences between ‘assistance’, ‘prompting’ and ‘supervising’, how variable conditions will be treated under PIP etc. and will be dissected in full in the next edition...

Winners and Losers

There will doubtlessly be some winners as well as losers under PIP - e.g. the current rigid barrier between DLA Lower and Higher Mobility has gone, so people with the most severe difficulties planning and following a journey could now theoretically get the Enhanced rate of Mobility. However a large number of people currently on DLA Higher Mobility now will drop down to the Standard rate of the PIP Mobility Component.

Within the Daily Living Component, inability to cook a main meal - currently one of the main qualifying routes for DLA Lower Care - will not now be enough in itself to result in an award of PIP. Some will lose benefit as a result, but others will be able to score other points elsewhere and actually get the Standard rate, which is likely to be paid at a level higher than DLA Lower Care.

The table below shows what the Government think the effect of introducing PIP will be, comparing claimant numbers for 2014/15 if everyone was on PIP—or if everyone was on DLA. You’ll notice that it’s not just recipients of DLA Lower Care dropping out: there are plenty of other movements going on...

DWP Assessment of the impact of the change to PIP			
Estimated PIP claimants 2014/15		Estimated DLA claimants 2014/15	
Enhanced Mobility, Enhanced Daily Living	340,000	Higher Mobility, Higher Care	350,000
Enhanced Mobility, Standard Daily Living	190,000	Higher Mobility, Middle Care	290,000
		Higher Mobility, Lower Care	270,000
Enhanced Mobility, No Daily Living	230,000	Higher Mobility, No Care	130,000
Standard Mobility, Enhanced Daily Living	110,000	Lower Mobility, Higher Care	170,000
Standard Mobility, Standard Daily Living	250,000	Lower Mobility Middle Care	450,000
		Lower Mobility, Lower Care	230,000
Standard Mobility, No Daily Living	190,000	Lower Mobility, No Care	50,000
No Mobility, Enhanced Daily Living	90,000	No Mobility, Higher Care	10,000
No Mobility, Standard Daily Living	250,000	No Mobility, Middle Care	40,000
		No Mobility, Lower Care	190,000
Total PIP Claimants	1,700,000	Total DLA Claimants	2,200,000

Some thoughts... overall

From a mental health perspective, there are three glaring problems with the PIP criteria:

- ‘Prompting’ - i.e. encouraging or reminding someone to do something consistently counts for less under PIP than ‘assistance’ - i.e. physical help to do something - does. This feels like a huge step backwards as it took years to get it established within DLA that the two sorts of help should be ‘worth’ the same.
- ‘Supervision’ criteria for qualifying for benefit are greatly reduced under PIP
- You can only score by needing help or prompting to actively do something under PIP. Needing prompting and encouragement *not* to do something won’t count.

and activity by activity...

Daily Living Component

1. Preparing food and drink

This echoes the cooking test for DLA Lower Care. Being unable to cook a main meal will however no longer score you enough points for an award in itself unless you cannot prepare any food or drink at all. On the other hand you may find you are able to pick up points elsewhere to achieve a ‘Standard’ award (probably) worth more than DLA Lower Care.. Note that prompting scores 2 but assistance/supervision score 4; if there are elements of risk involved then it’s definitely worth stressing this.

2. Taking nutrition

Under DLA, someone e.g. with an eating disorder, or whose eating was severely limited by depression could easily meet the requirements for either the Middle or Higher rate of Care based just on their need for ‘attention in connection with eating’. Under PIP though, someone, e.g. with anorexia might pick up 2 points here, but would need to also score from

other areas to achieve any award of benefit. I notice too that there are no ‘supervision’ points on offer here.

3. Managing medication and monitoring a medical condition

This, according to the DWP is the nearest PIP gets to the supervision test for DLA Care - as it includes monitoring your medical condition. The Guidance tells us that this is meant to include things like monitoring for deterioration, danger and self harm.

However most of the descriptors refer only to supervision to undertake medical therapy; unless things change then many people with significant supervision needs will only score one point.

Whilst there are other supervision points offered within other descriptors, these seem to relate more to risks involved whilst actually performing specific activities. A drastic re-think is needed.

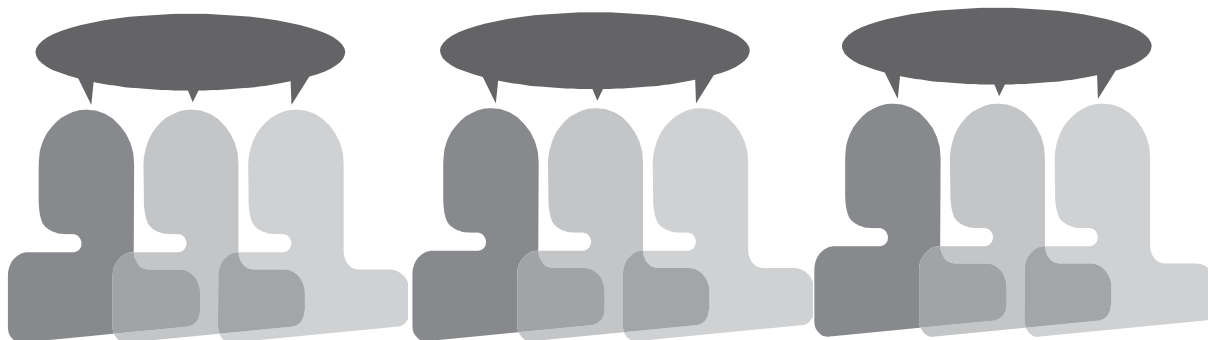
Meanwhile people who once got DLA largely on supervisory grounds will need to explore the rest of the scoring system carefully!

4 Bathing and grooming

One or two points on offer here depending on whether you need prompting to ‘groom’ or to ‘bathe’. Note that we’re talking posh here - to ‘bathe’ does not, according to the Guidance, mean to ‘bath’. What’s measured is your ability to keep your face, upper limbs and torso clean, no matter whether that’s through having a bath, a shower or simply a wash.

5. Managing toilet needs and incontinence

Not often of relevance within mental health - but if it is, it’s now worth a maximum of 2 points. By contrast I have, in the past, worked with people who have needed encouragement on and off through the day in connection with toileting, which would have been enough in itself to qualify them for DLA.



6. Dressing and undressing

Three potential ways to score here on mental health grounds - through needing prompting to dress or undress, to choose appropriate clothes or to know when you need to keep them on... No 'overt' points are offered for needing prompting to *change* ones clothes but I suppose you'd just argue that dirty clothes were not 'appropriate'.

7. Communication

On the face of it, this activity looks as if it's aimed only at people with problems with sight, speech or hearing. It's not though, so problems with poor concentration or memory, disordered thought processes or barriers to communication such as anxiety, paranoia or the distraction of hearing voices could all theoretically count here. Basic communication is defined as e.g. 'asking for help with an activity of daily living or understanding a simple safety instruction'. Complex communication is defined as being anything more complex than basic communication.

8. Engaging socially

Although this might look like a 'mental health friendly' activity, the Guidance defines 'social support' as *'support from a person trained or experienced in assisting people to engage in social situations'* - which to me sounds like something more than needing 'company' or the encouragement of a friend... The full 8 points are only available if your uncontrollable behaviour would lead to a risk to you or someone else, or if you are at risk of overwhelming psychological distress. *'There must be evidence that overwhelming distress has/ would occur, not just that it might'* adds the Guidance. DLA took a much wider view of social contact.

9. Making Financial Decisions

Complex financial decisions are defined by the Guidance as being anything more than buying something in your local shop and getting the

right change. Problems with budgeting, paying bills, uncontrolled spending etc. should then all count for 2 points. If panic, anxiety or other things get in the way of making a simple purchase then 4 points might be achievable.

Mobility Component

10. Planning and following a journey

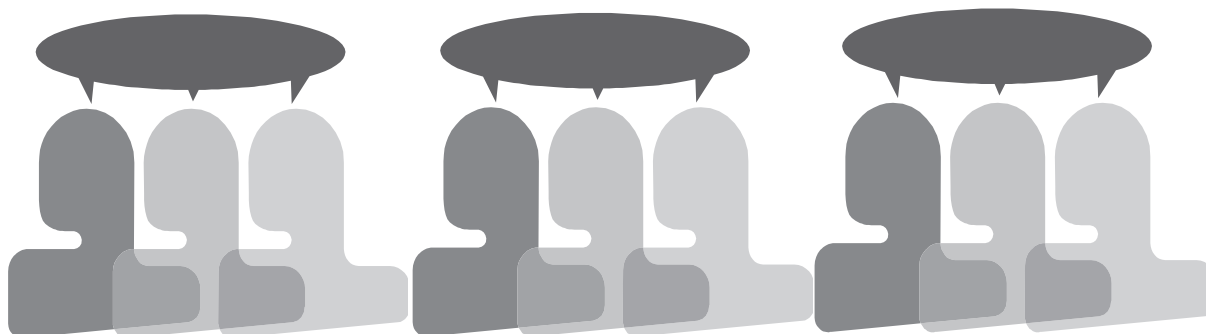
Many people on DLA Lower Mobility shouldn't have too much difficulty qualifying for the Standard rate of the Mobility Component on the basis of needing prompting or supervision to follow a journey to an unfamiliar place. And if someone has the same level of difficulty with familiar journeys they could now even possibly qualify for the Enhanced Mobility Component.

The logic behind the scoring of the two 'overwhelming psychological distress' descriptors is curious. In a way they sound more limiting rather than less limiting than the ones relating to needing prompting or supervision. If both apply, remember to argue for 8 or 15 Points rather than 4 or 11!

Unlike the DLA Mobility Component, PIP Mobility doesn't confine itself to *walking* outdoors. In fact the guidance specifically adds that *'a person should only be considered able to journey to an unfamiliar destination if they are capable of using public transport (bus or train)'*. Difficulties which were previously irrelevant then - e.g. feeling trapped or anxious on public transport - will now be quite important.

11. Moving around.

Many people who currently get DLA Higher Mobility because they are 'virtually unable to walk' will not get the Enhanced rate of PIP Mobility: similar difficulties will only score 8 points under PIP. The Enhanced rate is being reserved more or less for those who need to use a wheel chair all the time, or after 50 yards/ metres of walking. You can add any points scored here to any scored from Activity 10.



Moving from DLA to PIP:

Who and when?

People will not be 'migrated' from DLA to PIP in the same way as the move from the old sickness benefits to ESA has been handled.

It's envisaged, instead, that existing recipients of DLA will be 'invited' to apply for PIP:

- At any point where there is a change in their circumstances beyond October 2013; or
- When their existing award of DLA comes due for review; or
- Randomly - as picked by computer

The DWP are describing this as:

- 'Natural reassessment' – *'where an existing DLA claimant enters the reassessment process due to reporting a change in their care or mobility needs which might affect their award (know as supersession cases) or where a fixed-term award comes to an end'* and
- 'Managed reassessment' – *'where the Department initiates the reassessment process. We intend to select people randomly other than where they fall in to specific groups where a different timetable for reassessment may be required.'* (e.g. people approaching 65)

Unfortunately, writing back to the DWP thanking them for their kind invitation but expressing a polite preference for staying on DLA is not an option; less an 'invitation' and more an 'offer you can't refuse...' then.

How?

Once it's your turn for reassessment, you 'will be told' that your DLA will be ending and that you 'can instead make a claim to Personal Independence Payment.'

It's planned to allow a ridiculously short four weeks *'from the date that they are notified of their requirement to claim in which to do so'*. If you don't claim PIP within that time limit then the DWP will initially suspend payment of your existing DLA and give you a further 4 weeks to embrace the joys of PIP.

'If no contact is made by the claimant during this period then the claim to DLA will be terminated.'

'There will be limited appeal rights against the decision to terminate DLA, for example where there have been procedural irregularities, and safeguards will ensure that people who genuinely were not able to claim Personal Independence Payment within the time limits will be able to re-engage with the claiming process without penalty.' say the DWP.

All change...

- Migration of 'old' sickness route claimants to ESA - 'by 2014'
- Introduction of Personal Independence Payments for new claimants - 'from April 2013'
- Migration of existing DLA recipients to PIP - 'from October 2013'
 - ⇒ From October 2013:
 - any recipient of DLA reporting a change in their care or mobility needs will be invited to claim PIP
 - The DWP will begin inviting PIP claims from people whose DLA award expires from March 2014 onwards.
 - ⇒ Between October and December 2013—a 'Pathfinder exercise' of around 30,000 DLA claimants under the managed reassessment process.
 - ⇒ Reassessment to conclude by March 2016, although not all reassessments will have been completed 'until later that year'
- Introduction of Universal Credit for new claimants - 'from October 2013'
- Migration of existing income related ESA/ Income Support/ Income based JSA recipients to Universal Credit - 'from 2013 to 2018'



The gathering of information

At the time of writing we don't know what the PIP application form will look like, although it seems certain that it will be shorter than the current DLA one.

'We are currently considering what the claim will need to ask for, how the claim can be made and how we can support claimants through this process.' say the DWP.

One of the biggest changes proposed under PIP will be the introduction of face-to-face medical assessments for most claimants: *'We believe that advice from an independent healthcare professional, such as a doctor or occupational therapist approved by the Department, should be an important part of the new process. In most cases, we envisage that this will involve the individual having a face-to-face meeting with the healthcare professional, allowing an in-depth analysis of their circumstances'* say the Government.

The healthcare professionals concerned could be from Atos – the company currently paid by the DWP to be responsible for medical assessments or from a similarly contracted organisation.

It's an interesting definition of 'independent', isn't it - presumably meant to distinguish *these, Government funded* healthcare professionals from the ones directly involved in people's week-in-week-out care... the professionals specifically trained in mental health... the ones who see just how people are affected by their difficulties...

And even setting aside concerns about pipers, tunes and independence, how likely is it that a one-off assessment by a stranger - any stranger - will result in as complete a picture of an individual's difficulties as one compiled by someone's own Psychiatrist, CPN or Support Worker?

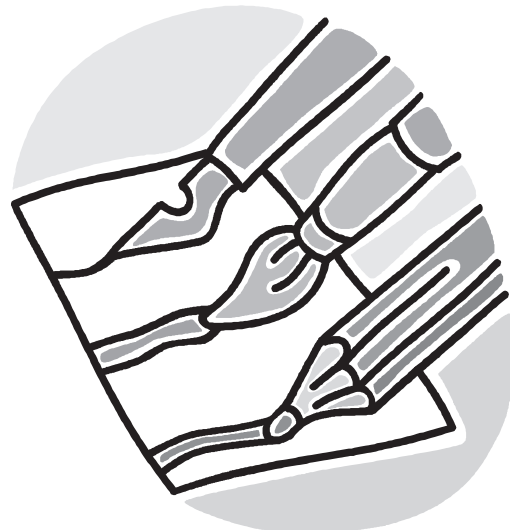
Not everyone will have to face these assessments though - away from the anti-claimant rhetoric, there are signs of a little common sense creeping in: *'We believe that, for the great majority of people, a face-to-face consultation between the individual and a trained independent assessor will play a key role in creating a fairer, objective and more transparent assessment for personal independence payment than that which currently exists under DLA.'*

'In particular, a face-to-face consultation will give individuals the opportunity to put across their own views of the impact of their impairment on their everyday lives' (Jude's note - ooh, just as currently happens within ESA assessments then...) *'and ensure that decisions reflect the best evidence. We do accept, however, that face-to-face consultations may not be appropriate in every case – particularly for those individuals with the most severe impairments. No decisions have been taken yet on the delivery model for the new assessment and we are still developing the new claims and assessment processes.'*

The Government have also promised to:

- allow applicants to nominate the people who *they* feel know most about their health problems
- ensure that the medical assessors are properly acquainted with the purpose and nature of PIP
- ensure that DWP decision makers weigh up all the information available to them

I suspect that strong supporting medical evidence sent with the claim will remain a powerful tool for those able to secure it.



Qualifying Period

In order to get PIP you will need to have had your problems for three months, just as with DLA. However you must also be likely to have that level of difficulties for the next nine months, rather than six months, which may make a difference to people with hopefully shorter term mental health difficulties.

People can of course also experience fluctuations in their level of difficulties. At the moment if you come off DLA because things improve but then get worse again, you can go back on DLA without waiting three months if this happens within two years of coming off DLA. It is proposed to cut this to one year under PIP.

The young and the old

Children are going to stay with Disability Living Allowance as their benefit for the time being. As they approach 16, young people will be invited to claim PIP.

As with DLA, there will be no new claims for PIP after the age of 65, but people getting PIP at 65 can carry on getting it (including any Mobility) rather than have to switch to Attendance Allowance.

If your mobility needs improve you will be able to drop down from Enhanced to Standard rate beyond 65, but you won't be able to move 'up' from Standard to Enhanced.

You will be able to move up or down the Daily Living component rates, or even claim Daily Living for the first time as long as you are getting PIP Mobility.

If you get better to the point where you come off PIP after 65, you can go back on to the benefit if things get worse again within one year of coming off the benefit, but only if it's because of the same medical condition. If more than a year has passed then you will have to claim Attendance Allowance.

Residence conditions

For DLA you have to be ordinarily present and resident in the UK. The Government proposes to replace this with the same, complex Habitual Residence Test used for means tested benefit. DLA also has a 'past presence' test in the UK - currently you have to have been in the UK for 6 months in the past year before you can claim. Under PIP it is proposed to extend this to 2 of the last 3 years.

Hospitals and residential Care

Broadly speaking the Government intends to keep the same restrictions as now on benefits in residential and hospital care, except that people in hospital or similar institutions will no longer be able to keep Enhanced PIP Mobility when they are paying this into a Motability agreement.

How much will PIP be worth?

So far there is no indication of what amounts will be attached to PIP, so it's anybody's guess.

We do know from other parts of welfare reform thinking though that the Government are keen to be seen to be targeting resources on the most severely disabled, so top rates of PIP may be higher than the highest rates of DLA, deflecting criticism of cuts elsewhere. They also seem keen on having a bigger gap between the Standard and Enhanced rates of PIP Daily Living Component than between DLA Middle and Higher Care.

PIP and Motability

At the moment, people awarded the Higher rate of DLA Mobility can choose to 'exchange' the cash award for a vehicle under the Motability Scheme. The Government have confirmed that the same arrangement will apply to people who get the Enhanced rate of the PIP Mobility Component. The Government's own estimates suggest that by 2014/15, over 500,000 people who would have been awarded the Higher rate of DLA Mobility will *not* be eligible for the PIP Enhanced Mobility Component.

PIP and other benefits

Any award of the PIP Daily Living Component will enable someone to claim Carer's Allowance for supporting the recipient.

Until Universal Credit takes over, within means tested entitlement any award of PIP will trigger a Disability Premium, an award of either rate of the Daily Living Component will trigger a Severe Disability Premium and an award of the Enhanced rate of the Daily Living Component will trigger an Enhanced Disability Premium.

At the moment, there are no plans for Universal Credit to include extra amounts linked to receipt of either DLA or PIP - see the relevant chapter for more details. This represents a real loss for many poorer disability benefit recipients who will not pass the ESA test which it's planned to use.

Conclusion

There will, inevitably, be individuals who gain financially under PIP and individuals who lose out.

For disability and mental health rights however - in my opinion - it's a lose - lose situation.

The passing of DLA sees the loss of a progressive, enlightened allowance which did exactly what it said on the box - it allowed people facing the extra costs associated with long term illness or disability to live rather than to merely exist.

It took a social rather than a medical view of disability and - for the first time - allowed people to describe how *they* were affected by their health problems rather than relying on medical assessment by a stranger.

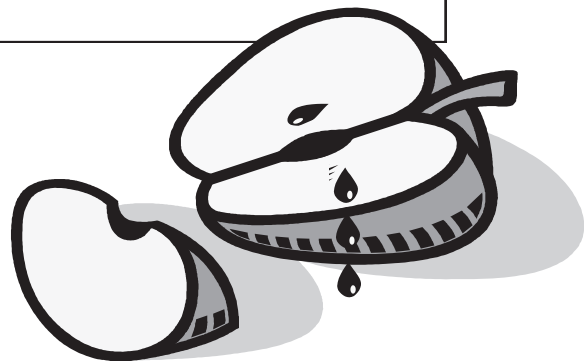
And refined by caselaw, it became a benefit under which - within the Care Component at least - people limited by health issues were treated equally, whether their difficulties stemmed from physical or mental health problems.

No points based system could ever hope to have the flexibility - or potential for common-sense application - as is offered by the brief and elegant regulations used to decide eligibility for DLA.

PIP goes beyond though, overtly and consistently treating mental health needs as having less value than physical ones, and introducing medical assessment for most applicants.

As a result, some people will be put off claiming PIP in the first place, and some people who ought to receive it won't: the inherent problems of "snapshot" medical assessments which have dogged ESA and IB before it will be replicated, not resolved

Next year's Big Book will of course bring you all the usual guidance, tactics, example forms and letters to help in applying for PIP - but in the meantime join me in raising a glass, cup or mug to mark the passing of DLA and the difference it made to people's lives...



Common Mental Health Diagnostic labels/ symptoms – a very brief guide for disability benefits...

WARNING! Psychiatric diagnosis is *not* an exact science. The diagnoses which result are simply applied to people who experience some or all of a collection of symptoms associated with a particular diagnostic label.

Psychiatric diagnosis also reflects prejudices associated with gender, culture and sexual persuasion within society e.g. – women are more likely to be given a diagnosis of Borderline Personality Disorder than men. Black people are more likely to be diagnosed as having schizophrenia. Homosexuality only disappeared from the list of ‘disorders’ (sic) contained in the DSM (see below) in 1974.

Most of the world of psychiatry uses the ‘*Diagnostic and Statistical Manual of Mental Disorders*’ as its standard frame of reference. Currently in its fourth incarnation since it was first developed in the 1950s, DSM-IV (published in 1992) lists 265 categories of disorder. DSM-V is due out in 2013 - excerpts from it as well as the chance to comment - can be found at www.dsm5.org.

Psychiatry has historically (and some would say hysterically...) divided mental health problems broadly into ‘neuroses’ and ‘psychoses’. ‘Neurosis’ is a term used to describe anxiety states and depressive problems. ‘Psychosis’ is used to describe a state in which someone’s ability to tell what is ‘real’ is affected... e.g. seeing things, hearing voices, believing someone is trying to harm you, ‘delusional’ ideas etc.

Please then don’t think of the next few pages either as an endorsement of the way Psychiatry labels things OR - most importantly - as a ‘self diagnostic’ tool for yourself or anybody else; it’s simply a guide to the types of difficulties people labelled with each diagnosis MIGHT experience.

In the meantime if you want in-depth information about any of these or other diagnoses, National Mind produce very good ranges of leaflets which can be accessed for free via their website - www.mind.org.uk

Anxiety

Everyone experience a certain amount of anxiety – e.g. before interviews, worries about specific events – but it usually goes away once the cause of the stress is over. People suffering from anxiety states either can’t shed the anxiety at all, or find it is caused by things that wouldn’t stress other people. Although often treated dismissively, anxiety can be overwhelming and can put very real limitations on people’s lives.

Typical difficulties usually include:

- problems being alone
- difficulties coping with unfamiliar settings
- problems dealing with crowded settings
- panic attacks
- ‘fight or flight’ responses to anxiety
- problems concentrating on doing things - cooking/ dealing with paperwork/ reading/ completing tasks etc.
- problems remembering things - tablets/ messages etc.
- wanting to stay in or return to the ‘safety’ of bed
- problems with motivation/ self care because of distraction/ exhaustion
- lack of appetite/ feeling ‘too sick’ to eat
- difficulty taking things in/ remembering things because of constant worries in mind
- loss of confidence/ problems dealing with other people/ avoiding social contact
- feeling overwhelmed by things
- problems with ‘waiting’ - in queues/ waiting rooms etc
- problems sleeping

Anxiety is often found in combination with depression - see the next page.

Depression

Depression is more than a lowness of mood. At its worst, it is a bleak, isolating vacuum where suicide can seem the only way out - almost a kindness to other people. At best it can make it very hard for people to motivate themselves to function in an 'ordinary' way.

Depression is often classified by psychiatry either as 'reactive' - which means it is a reaction to something that has happened in someone's life - or 'clinical' - where there is no obvious root cause for someone's feelings. People with 'clinical depression' often have recurring bouts.

Typical difficulties usually include:

- lack of energy/ utter lethargy
- wanting to stay in bed/ returning to bed during the day
- lacking motivation for self care (what's the point? etc.)
- problems with concentration - see list of activities under 'anxiety'
- no self-confidence/ self-worth - avoiding social contact, isolating oneself
- ignoring health needs/ problems
- forgetting things
- sleep problems
- loss of appetite
- suicidal thoughts/ ideas/ attempts

often appears in diagnoses hand-in-hand with anxiety



Self Harm

Self harm can technically cover anything from neglecting one's own physical or emotional needs through to deliberate self-injury (cutting, burning etc). It's usually in this latter sense that the psychiatric profession use it.

The wish to hurt oneself in this way is very different to suicidal feelings - people who self harm often describe it as a coping or even a 'survival' strategy which they feel helps them to deal with their emotional pain. A high proportion of people who self-harm have been sexually abused, often in childhood.

Having said that, a proportion of people who self harm do eventually go on to experience suicidal thoughts/ attempt to take their lives.

People who self harm often encounter prejudice and lack of understanding from others.

Because most self-harm is not *immediately* life-threatening, in benefit terms applications based on self-harm often mean having to explain the longer term risks to the DWP...

- I burn/ cut myself with razor blades/ knives/ glass - I have ended up with nasty infections
- I have cut myself so deeply that I have damaged tendons
- If I cut/ burn myself when I've been drinking I sometimes go too deep
- I don't feel able to go to the doctor when I've done this - they don't understand
- My doctor doesn't understand - so I don't go to them about other health worries either
- I've ended up trying to stitch up my own cuts - I have awful scarring
- The skin on my arms/ thighs has become so scarred that it doesn't have normal stretch to it
- partially healed cuts open up very easily

If you self harm you may well also be able to relate to some of the difficulties listed under 'anxiety' or 'depression'.

Eating disorders

The diagnoses you'll commonly encounter are bulimia and anorexia. Bulimia suggests binge eating whereas anorexia centres around food refusal/ extreme dieting. People with either diagnosis may deliberately induce vomiting, over-exercise or misuse laxatives.

There is a clear route into DLA care via encouragement to eat and also supervision/ encouragement NOT to binge/ vomit/ use laxatives/ over exercise - potentially at any time of day or night. Most people diagnosed with eating disorders will be extremely secretive about doing these things, so a very high degree of supervision may be needed to guard against them.

Risk factors include damage to teeth/ gums/ oesophagus and larynx associated with repeated exposure to stomach acid, bowel incontinence, malnutrition, infertility, stunted growth, osteoporosis, heart problems/ failure, kidney failure and, ultimately, death.

- I don't eat enough - my weight has gone as low as
- I take lots of laxatives. My nurse says this is affecting my bowel continence
- I starve myself for weeks as a sort of 'control' thing
- I have anaemia/ gum disease/ stomach problems as a result
- I 'binge' on food and then make myself sick – this is affecting the balance of chemicals in my body and my teeth are rotting because of stomach acid
- I try to hide what I'm doing



Post Traumatic Stress Disorder (PTSD)

PTSD is often found in people who have served in the forces because its 'root' is thought to come from exposure to some sort of extreme horror/ violence. It can, though, equally affect *anyone* who has experienced or witnessed trauma – e.g. terrible accidents, bombings, fires, disasters or, equally, rape, personal assaults or abuse.

For a while after such an incident, it is considered 'normal' for certain everyday 'triggers' – be they sounds, smells or visual associations - to bring back memories, feelings and emotions associated with the event. This, though, normally fades. PTSD is what is diagnosed when it doesn't.

It's very common for PTSD to be found in combination with depression, anxiety, phobias or dissociative disorder, although you'll often find that people haven't been given both diagnoses - so see those sections too

Common symptoms of PTSD include:

- Distressing flashbacks
- Tearfulness/ shaking
- Nightmares/ poor sleep
- Intrusive thoughts/ memories/ pictures
- Panic
- Being very 'jumpy'
- Feeling detached/ numb
- Feeling constantly on edge
- Hopelessness
- Guilt
- Problems with concentration

In disability benefit terms, people most usually qualify for the mobility component because of sudden panic, distress and/ or aggression if something triggers their PTSD whilst outside.

You may also be eligible for the care component on 'attention' grounds because your state of mind gets in the way of self care/ communication/ thinking/ sleeping or on supervision grounds because of aggressive behaviour associated with flashbacks/ intrusive thoughts/ nightmares, suicidal feelings or doing things that might be dangerous.

Obsessive Compulsive Disorder (OCD)

OCD can be very distressing and *massively* frustrating. Most people – often when feeling stressed or that life is somehow out of control – experience minor obsessions or compulsions – e.g. the need to check something repeatedly, or the need to put things in order... In OCD however (which affects around 3 per cent of the population) these feelings are so magnified that they can *severely* disrupt everyday life.

Obsessions can include:

- fear of dirt, germs or contamination
- needing things to be perfect (cleanliness or orderliness- wise)
- the need to confess things (verbally or in writing) – and the fear of doing so
- imagining upsetting or harming others
- intrusive sexual urges / taboo thoughts
- fear of your own potential for aggression

Common compulsions:

- washing
- checking
- cleaning
- counting
- touching
- not touching
- arranging/ ordering/ tidying
- ‘ritualistic’ behaviour
- hoarding things

Applications for DLA often need to be based around the disruption caused by the OCD, along with the physical effects

- I can't cope outside without company – the OCD makes everything painfully slow and on my own I often get 'stuck' in the need to check things
- I feel too embarrassed to go to places because sometimes I can't get through the door



- I am terrified I will upset people I talk to / harm people in the street
- I telephone people repeatedly – sometimes in the night – to check I haven't upset them
- I can't cook for myself because the mess it makes is too stressful
- I can't post anything because I fear I will have written something inappropriate in it
- The obsessive washing/ checking/ cleaning/ counting etc mean that I am not able to move around my home 'normally' – reassurance/ being distracted by someone helps
- Left to myself I clean for so many hours that I become utterly exhausted
- My skin is raw and cracked from all the washing/ contact with cleaning fluids

Dissociative Disorders

The term ‘dissociative disorders’ covers a number of controversial sub-diagnoses – e.g. Depersonalisation Disorder, Dissociative Amnesia, Dissociative Fuge, Dissociative Identity Disorder (once known as ‘Multiple Personality Disorder’)

In common, they all involve some sort of disruption of memory, awareness, identity and/or perception. Some believe that they develop as a sort of ‘coping strategy’, distancing a person from distressing things that have happened to them, often in childhood. Many people eventually diagnosed with a dissociative disorder have previously been given other diagnoses.

Associated symptoms include:

- Depersonalisation – feeling unreal – as if watching yourself on film – or that your body is changing in some way, or not ‘yours’ or not ‘there’
- Derealisation – feeling that the world or your environment is in some ways unreal, or seeing things change/ appear/ dissolve
- Amnesia – forgetting information/ incidents or losing blocks of time
- Identity Confusion
- Identity Alteration – Behaving very differently in different settings, or feeling you have more than one person inside

It’s impossible to generalise about common ‘attention’ type difficulties for Disability Benefit purposes because the dissociative disorders cover such a broad spectrum, are often found in association with other diagnoses and affect people to a widely varying degree. Difficulty communicating with others is however fairly widespread.

The mobility component and the ‘supervision’ route to the care component may well be accessed on the grounds that people with this diagnosis may self harm, may have suicidal feelings or may use drink/ drugs to try to help the way they feel.

Personality Disorder

Another controversial cluster of diagnoses, the common theme being very rigid patterns of thought, action and reaction which affect people’s ability to interact with others.

The DSM-IV groups ten different personality disorders into three groups – eccentric disorders, dramatic, emotional or erratic disorders and anxious or dependant disorders.

Individuals with this label may have markedly different perceptions of themselves and the world, emotional responses which are not what society would usually expect, problems relating to other people and difficulties controlling their impulses. People with personality disorders have traditionally been considered ‘untreatable’ by the world of psychiatry – and so often have not received much support from those who run services. Attitudes are, however, changing slowly.

The one most likely to be encountered in benefits work is ‘Borderline Personality Disorder’. The ‘borderline’ here *doesn’t* refer to someone being ‘just a little bit unwell’ (something you may have to remind decision makers about!), it refers to the ‘borderline’ between neurosis and psychosis.

People with a diagnosis of Borderline Personality Disorder may experience:

- Terrible fears of being abandoned
- A history of intense/ unstable relationships within which they can switch from worshiping and idolising people one day to treating them as if they are worthless the next
- Impulsive tendencies which may be damaging – e.g. substance misuse, eating disorders, promiscuity, gambling, recklessness
- Self harm, suicidal feelings and/ or actions
- Extreme moods, including anger
- Paranoia and feelings of victimisation, worthlessness
- Severe dissociation

It is often then on supervisory grounds that people might qualify for both the mobility and care components of disability benefits.

Schizophrenia

The 'positive' symptoms associated with schizophrenia can be very distressing to experience. They include:

- hearing voices (most often unfriendly, abusive or critical, but not always)
- feeling that your thoughts are controlled by others and/ or being 'inserted' into your head
- believing your thoughts are known to others
- feeling people want to harm you / kill you
- having unusual 'explanations' for what you are experiencing – e.g. religious ideas, possession...

There are also 'negative' symptoms including:

- apathy
- blunted or inappropriate emotional responses
- social withdrawal
- poor motivation

These negative symptoms often remain even when the positive ones are controlled by drugs.

Establishing entitlement to disability benefits then - especially if your 'positive' symptoms are mostly kept in check - can depend on explaining as fully as possible how your continuing negative symptoms impact on your personal care, ability to communicate, socialise etc and the verbal encouragement/ support that could help with this.

Do include, though, information about how you are when you're more affected by the positive symptoms too, including telling them if you've been admitted to hospital or if there's been some sort of risk involved - e.g. behaving in a way that others perceive as 'odd' may put you at risk of ridicule/ attack. (See the full list under 'someone keeping an eye on you' earlier this chapter). The side-effects of the drugs you're prescribed may also cause you difficulties - remember to include them too.

People who are receiving 'depot' injections will usually have been irregular at taking tablets in the past - although some Consultants simply seem to 'prefer' their patients to be on injections...

A diagnosis of 'Schizoaffective disorder' means that symptoms of Schizophrenia are coupled with either manic or depressive mood alteration.

Manic Depression/ Bi-polar disorder

Manic depression causes profound alterations of someone's mood – from severe, at times life-threatening depression to exuberant elation. People may also experience delusional thinking and auditory or visual hallucinations.

People affected may put themselves at risk through:

- believing they are invincible (e.g. – have special powers, can fly, can control traffic...)
- becoming sexually disinhibited (sometimes with bizarre dressing)
- acting on grandiose ideas (taking on loans, setting up businesses, going off to the other end of the world)
- becoming combative or even aggressive

During periods of both low and high mood, people may neglect their personal care - indeed the depression associated with bi-polar disorder can be so crushing and complete it can virtually keep people bed bound.

The justification for both verbal encouragement/ support and supervision when most unwell is fairly obvious then. Between periods of highs or lows though you may be relatively well, so where disability benefits are concerned it's often a case of spelling out the risks and stressing that deterioration can happen very quickly...

- When I lose it I don't know what I'm doing/ can't remember what I've done
- I do stupid things - like climb onto the roof of a building
- I thought I could fly...
- I walked out into the road because I was convinced I could stop the traffic
- I spend money I just haven't got
- I give my money away to other people
- People take advantage of me
- I sometimes go off to big towns - I've spent weeks/ months living on the streets
- I end up with people I shouldn't go with - my support worker says I am very vulnerable

See also the pages between the two sets of sample DLA forms at the end of the chapter.

Hope this is useful...

What follows are two sets of ‘example’ pages from the DLA forms. This doesn’t mean they are *shining* examples - just suggestions that you *may* look at and *may* find useful!

Of course everyone’s mental health problems are different, and I wouldn’t suggest for a minute that everything in one of the forms will apply to you. Hopefully though, using them in conjunction with the listings of ‘difficulties’ on previous pages, you’ll at least find it easier to fill some of those very blank boxes!

DLA and Anxiety/ Depression

The first set of pages were completed with the sorts of difficulties you may have when you feel anxious/ depressed. The imaginary person whose form this represents also self-harms.

DLA and Psychosis

The second ones relate more to hearing voices and experiencing frightening thoughts - with some notes at the start about various diagnoses that fall under the heading of ‘psychosis’. Sandwiching the two are some hints for people completing forms who have been diagnosed with Bi Polar Disorder/ Manic Depression.

Your feedback, please...

As always I would be really grateful to hear how helpful - or otherwise - you have found the ideas, checklists and sample forms in this chapter - along with any suggestions for change or improvement - please keep the feedback coming...

