

# **Personal Independent Payment**

# Guide to Completing PIP 2 How Your Disability Affects You

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NB: This publication was correct at the time of printing, but benefits law frequently changes so this guide should be used in conjunction with independent benefits advice.

# Personal Independent Payment Guide to Completing PIP 2 - How Your Disability Affects You

This form is your chance to explain how your disability or long term illness affects you. To be awarded PIP you need to score enough points from a list of descriptors:

# Daily Living Component: Standard Rate – 8 points; Enhanced Rate – 12 points Mobility Component: Standard Rate – 8 points; Enhanced Rate – 12 points

If you indicated during your initial new claim phone call (or as can be sent in 'exceptional circumstances' your initial paper claim form - PIP 1) that you suffer from mental health problems, behavioural problems, learning disabilities, developmental disorders or memory problems and do not return this form you will still be invited to a 'face-to-face assessment'. If you have not indicated any of these problems and do not return the form within a month without 'good reason', you will be found not to qualify for PIP and your claim will be refused.

BUT still complete the form even though you may have these problems because it is your chance to give your account of your problems. If there is enough evidence (not just the form but backed up with evidence from any professionals involved in your care or treatment), you may be awarded PIP without having a 'face to face assessment' and even if this is not the case it is your chance to make sure it is not just the healthcare professional's opinion that is put before the DWP decision maker (or appeal panel).

Remember to include with this form (or forward later if necessary) any supportive evidence you can obtain to support your claim eg; letter from GP, Mental Health Nurse, Psychiatrist, Social Worker, Support Worker, or your carer—evidence is not restricted to information from medical professionals.

The 'Point Score' and Fluctuating Conditions: You will be awarded points in each activity provided the descriptor applies on over 50% of the days in the 'required period' (previous 3 months and following 9 months after claim date). If more than one descriptor in an activity applies for at least 50% of that period the highest score will be awarded. If no descriptor applies for 50% of the days but a combination add up to 50% of the days, points will be awarded for the descriptor that applies on most days. If a combination adding up to 50% of the time apply on an equal number of days each the higher score will be awarded.

**Aids and Appliances:** All the daily living and mobility descriptors are considered on the basis of you wearing or using any aid or appliance, including artificial limbs, you either normally use or could reasonably be expected to use. If you use an aid or appliance out of preference but do not need to the guidance states you should be treated as being able to do the activity unaided—explain why it IS

needed. If you do not use an aid or appliance, the guidance states it should be considered if you manage the activity reliably with an easily available one instead of assistance or supervision. Aids and appliances include things that are not specially designed for disabled people, e.g. an electric can opener.

**Night-time Care Needs:** Although called 'daily living activities', needs should be looked at over a 24 hour period and night-time needs taken into account.

**Prompting:** This is defined as 'reminding, encouraging or explaining by another person'. The healthcare professional's (HCP) guidance describes prompting as another person reminding or encouraging the claimant to undertake or complete a task or explaining how to but not physically helping, to apply this only needs to be required for part of the activity.

**Assistance:** This is defined as meaning 'physical intervention by another person and does not include speech'. The HCP guidance describes assistance as requiring the presence and *physical intervention* of another person to help the claimant complete the activity which can include doing some of the activity for them and only needs to be required for part of the activity.

Therefore people with mental health problems who can physically do the activity but need prompting to actually do it, will be restricted to the points for 'prompting' - which are generally lower than the points awarded for 'assistance'.

**Supervision:** Is defined as 'the continuous presence of another person for the purpose of ensuring safety'. The HCP guidance says supervision must be needed to avoid a 'serious adverse event' occurring to the claimant which would be likely to occur if there was no supervision. The supervision must be needed for the full duration of the activity.

**Reliably:** You can only be treated as able to do something if it can be performed 'reliably'. You must be able to do it Safely; To an acceptable standard; Repeatedly; and In a reasonable time period.

The regulations define 'safely' as meaning 'in a manner unlikely to cause harm' to self or others during or after completion of the activity. 'Repeatedly' means 'as often as the activity being assessed is reasonably required to be completed'. Factors such as pain, fatigue, motivation etc will affect whether an activity can be completed reliably and it is important to explain these problems both in the face-to-face consultation and on the 'tell us how your disabilities affect you' form.

This guide give details of how the terminology used in the descriptors is legally defined in the regulations, plus guidance given in the PIP Assessment guide for healthcare professional's (HCP) - this guidance was updated on 31/10/14 and became more restrictive in some areas and updated again on 28/07/15 with increased emphasis on aids—but remember this is guidance only NOT law and you can still use the earlier guidance. We have also given some of our ideas of when the descriptors may apply.

Tell us in Questions 3 to 15 how your health conditions or disabilities affect your day-to-day activities.

#### Q3 Preparing Food

#### (i) Use page 6 of the Information Booklet

Please tell us about your ability to prepare a simple one course meal for one from fresh ingredients. This includes things like:

- food preparation such as peeling, chopping or opening a can, and
- safely cooking or heating food on a cooker hob or in a microwave oven.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q3a Do you use an aid or appliance to prepare or cook a simple meal?

Aids and appliances include:

• perching stools, lightweight pots and pans, easy grip handles on utensils, single lever arm taps and liquid level indicators.

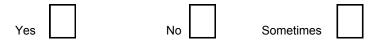
Yes	No	Sometimes	

#### Q3b Do you need help from another person to prepare or cook a simple meal?

Help includes someone:

- · physically assisting you to prepare to cook food,
- cooking your food for you,
- supervising you to make sure you are safe, and
- prompting, encouraging or reminding you to cook food or how to do so.

This includes help you have and help you need but don't get.



#### Q3 Extra information - Preparing Food

Tell us more information about the difficulties or help you need to prepare and cook food. For example, tell us things like:

- If you cannot do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind (for example whether they need to remind or motivate you to cook, plan the task for you, supervise you while you are doing it, physically help you or prepare all your food for you).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you can only cook using a microwave.
- If your ability to do it varies, tell us in what way and how often for example, telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity - like pain, breathlessness or tiredness.

If you put something in the box below you don't have to fill all of the box



# **Daily Living**

1. Preparing Food	
a. Can prepare and cook a simple meal unaided	0
b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal	2
c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave	2
d. Needs prompting to be able to either prepare or cook a simple meal	2
e. Needs supervision or assistance to either prepare or cook a simple meal	4
f. Cannot prepare and cook food	8

The law has defined what certain terms mean:

Cook: means ability to heat food at or above waist height

**Prepare**: means getting the food ready for cooking or eating, therefore includes activities such as peeling and chopping vegetables and opening packaging.

Simple meal: means a cooked one course meal for one using fresh ingredients.

Under the old Disability Living Allowance rules, you could be awarded lower rate care • for difficulties preparing and cooking a simple meal, including the use of an oven, now this will need to be combined with difficulties in other activities unless you cannot • prepare and cook food at all.

The cannot prepare and cook food descriptor, given the guidance issued regarding the lower point scoring descriptors, is likely to be interpreted as meaning 'cannot at all' and therefore only likely to be used for people with very severe learning difficulties or severe physical problems which mean that even with physical assistance or supervision they would still not be capable. The 8 point descriptor refers to just food instead of the ability to make a simple meal.

This activity does not look at whether you are able to safely bend to get food in or out of an oven; it just considers the ability to use a hob or microwave. The HCP guidance states this activity does not include carrying items around the kitchen, but this is not law, just guidance and some moving things around the kitchen is needed to prepare and cook a simple meal. It does though include the ability to serve food on a plate.

The guidance for healthcare professional's gives examples of aids and appliances including using prostheses, a perching stool, lightweight pans, easy grip handles, single lever arm taps, spiked chopping boards. A perching stool is stated as an aid—consider

issues such as safely getting on/off the stool.

Although pre-chopped vegetables are not considered an aid or appliance, being reliant on them may show that you could be considered as requiring either an aid or appliance or help from another person to complete the activity.

If an aid or appliance is used the guidance says the health professional should consider whether it MUST be used to do the activity reliably or used to make it easier but is not required so no points for using one. This is emphasised throughout the guidance and is probably most relevant to preparing and cooking food, as this is an activity where gadgets are often used for convenience.

The guidance says prompting may apply if you lack the motivation to cook, need to be reminded how to prepare and cook food or need to be reminded how to cook and prepare food on the majority of days– descriptor D. Descriptor E—includes needing supervision if unable to tell if food is safe to eat e.g. meat cooked. Descriptor C - if you could not safely use the hob—such as leaving the cooker on, but when using a microwave, the health professional should still consider the ability to prepare the meal.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliably affects the different activities:

Safely:

- 'increased risk of cutting oneself or another person as a result of a health condition or impairment'
- Fire risk from not understanding how to use an electrical appliance or gas hob correctly.
- Burning or scalding oneself on pans or spills if for example you are likely to drop a saucepan or spill food.
- 'an actively suicidal person may require supervision to carry out these activities or be unable to carry them out at all, due to the risk of self harm posed by access to knives, naked flames, hot implement and food' - stating that a person in this situation is 'likely to have a care plan'. Guidance states supervision due to a significant risk of self-harm is covered by descriptor E.

# To an acceptable standard:

- Ability to make a simple cooked meal for one prepared from fresh ingredients which is edible and properly cooked—functional skills not choice whether to cook.
- Not about cooking ability so issues such as presentation don't count.

# **Repeatedly:**

• If you can prepare a meal, but the exhaustion from doing so means you can only do it once a day you cannot do it 'repeatedly' (ie as often as required).

# In a reasonable time period:

• Example given is: physically capable of preparing a meal, but the need for formalized ritual means it takes all morning to prepare breakfast

#### Q4 Eating and drinking

#### (i) Use page 7 of the Information Booklet

Please tell us about your ability to eat and drink. This means:

- remembering when to eat,
- cutting food into pieces,
- putting food and drink in the mouth, and
- chewing and swallowing food and drink.

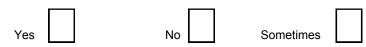
We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information Box.

#### Q4a Do you use an aid or appliances to eat and drink?

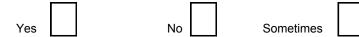
Aids and appliances include things like:

• adapted cutlery



#### Q4b Do you use a feeding tube or similar device to eat or drink?

This means things like a feeding tube with a rate limiting device as a delivery system or feed pump.



### Q4c Do you need help from another person to eat and drink?

Help includes someone:

- cutting your food into pieces or putting food in your mouth,
- supervising you to make sure you don't choke,
- prompting, encouraging or reminding you to eat or drink, and
- helping you manage a feeding tube.

This includes help you have and help you need but don't get.



#### Q4. Extra information - Eating and drinking

Tell us more information about the difficulties or help you need to eat and drink. For example, tell us:

- If you cannot do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind (for example whether they need to prompt, remind or encourage you to eat, supervise you when you eat, cut food up for you or put food and drink in your mouth).
- If you use aids and appliances, tell us what type they are and how you use them.
- If your ability to eat and drink varies, tell us in what way and how often for example telling us about good days and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness or tiredness.

If you put something in the box below you don't have to fill all of the box.



2. Taking Nutrition	
a. Can take nutrition unaided	0
<ul> <li>b. Needs:</li> <li>(i) to use an aid or appliance to be able to take nutrition or</li> <li>(ii) supervision to be able to take nutrition or</li> <li>(iii) assistance to be able to cut up food</li> </ul>	2
c. Needs a therapeutic source to be able to take nutrition	2
d. Needs prompting to be able to take nutrition	4
e. Needs assistance to be able to manage a therapeutic source to take nutrition	6
f. Cannot convey food and drink to their mouth and needs another person to do so	10

The law gives definitions:

**Take nutrition**: means to either 'cut food into pieces, convey food and drink to one's mouth and chew and swallow food and drink' or 'take nutrition by using a therapeutic source'.

**Therapeutic source**: is defined as meaning parenteral (other than through the mouth) or enteral (into intestines) tube feeding, using a rate-limiting device such as a delivery system or feed pump.

Remember if you need physical help to use the therapeutic source at any time it is very important to explain this to show how you meet the higher scoring descriptor.

The guidance states that the type of food or drink should not be considered but the 'claimant's ability to nourish themselves'. The guidance also states that the 'frequency of taking nutrition should only be considered if the claimant has an eating disorder, supported by further medical evidence'. Both these statements are only guidance and not law and therefore help needed to eat sufficiently nutritious food or eat often enough can and should be explained, as you can argue it counts.

The government's guidance says that when assessing whether supervision is required 'whether the claimant has a real risk of choking' should be considered. This could apply to someone who has regular seizures or has throat problems. The risk of choking would need to be due to your health condition or disability.

The government have said that motivation to eat is taken into account by whether a claimant can complete this descriptor 'reliably', although they have also stated that prompting to take nutrition will only qualify if prompting is essential for you to complete the activity although the prompting can occur at any point. Therefore if you need encouragement to start eating, and would often not get round to eating without this encouragement, the activity would not be completed. Explain how often you miss meals and explain why e.g. 'I get so down, that due to my depression I just don't want to eat'.

The guidance for healthcare professionals describes prompting as applying if you need reminding to eat or need prompting about portion size.

This is an important activity for some mental health problems, as the prompting descriptor equals 4 points. Lacking the motivation to eat can affect people with depression or substance dependency etc as well as people with eating disorders; if your health means you are not eating properly, —explain this here.

The guidance on prompting about portion size means this descriptor could apply to different types of eating disorders, whether eating too little or bingeing as a result of your health condition or disability. The guidance states 'prompting regarding portion size should be directly linked to a diagnosed condition such as Prader Willi Syndrome or Anorexia. In cases where obesity is a factor through the claimant's lifestyle choices then this descriptor would not apply'. This is a very simplistic view of eating problems and it is important to fully explain why prompting is required for other health reasons and do not be restricted to just diagnosed eating disorders.

**Reliably:** the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities: **Safely:** 

• Risk of choking on food.

# To an acceptable standard:

- The outcome of this activity is being nourished, by cutting food into pieces, conveying it to the mouth, chewing and swallowing; or using of therapeutic sources.
- 'Spilling food can be considered, regular spillage requiring a change of clothes after meals is not an acceptable standard of taking nutrition'.
- It is not necessary to be able to cut up tough meat like steak to do the activity to an acceptable standard.

#### Q5 Managing treatments

### (i) Use page 7 of the Information Booklet

Please tell us about your ability to monitor changes in your health condition, take medication or manage any treatments carried out at home.

Monitoring changes includes monitoring blood sugar level, changes in mental state and pain

levels.

Home treatments include things like physiotherapy and home dialysis, regardless of whether these are NHS or private.

We want to know if you can do this safely, to an acceptable standard, as often as you need

to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

# Q5a Do you use an aid or appliance to monitor your health conditions, take medication or manage home treatments?

For example using a Dosette Box for tablets.

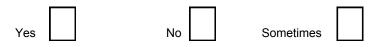
Yes No Sometimes	Yes	No	Sometimes	
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# Q5b Do you need help from another person to monitor your health conditions, take medication or manage home treatments?

Help includes someone:

- prompting or reminding you to take medication or how to do it,
- supervising you while you take medication,
- physically helping you to take medication or manage a treatment, and
- monitoring your mental state.

This includes help you have and help you need but don't get.



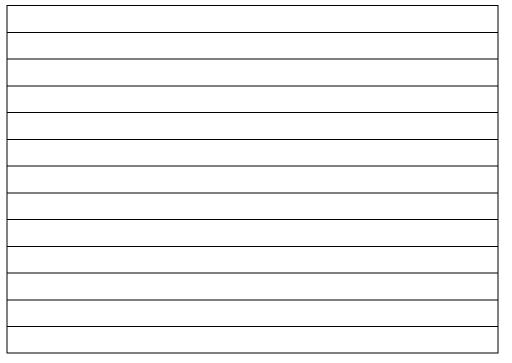
#### Q5 Extra information - Managing treatments

Tell us more information about the difficulties or help you need to monitor your health conditions, take medication or manage home therapies.

For example, tell us:

- If you cannot do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you use aids and appliances, tell us what type they are and how you use them.
- If you need help from another person what kind of help you need (for example whether they need to prompt or remind you to take medication or treatment, physically help you or supervise you taking medication or treatment or help you monitor your mental state).
- If you need help from another person, tell us how many hours a week of help you need on average.
- If your needs vary, tell us in what way and how often for example, telling us about good and bad days or how it varies throughout the day.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness or tiredness.

If you put something in the box below you don't have to fill all of the box.



<b>3. Managing Therapy or Monitoring a Health</b>	
Condition	
<ul> <li>a. Either:</li> <li>(i) does not receive medication, therapy or need to monitor a health condition or</li> <li>(ii) can manage medication, therapy or monitor a health condition unaided</li> </ul>	0
<ul> <li>b. Needs either:</li> <li>(i) to use an aid or appliance to be able to manage medication or</li> <li>(ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition</li> </ul>	1
c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week	2
d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week	4
e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week	6
f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week	8

The law defines:

**Medication**: as needing to be prescribed or recommended by a registered doctor, nurse or pharmacist.

**Therapy**: is defined as being under taken at home (in a domestic setting) and needing to be prescribed or recommended by a registered doctor, nurse, pharmacist or health professional regulated by the Health Professions Council (HCP) (renamed the Health and Care Professions Council, which includes professions such as occupational therapists, physiotherapists, speech therapists, the full list of professions is detailed on <u>http://www.hpc-uk.org/</u>).

**Monitor Health**: to detect significant changes in the claimant's health condition which are likely to lead to a deterioration in their health and take action advised by a doctor, nurse or health professional (regulated by the HCP as detailed above) without which their health is likely to deteriorate.

**Manage medication or therapy**: means take medication or undertake therapy where a failure to do so is likely to result in a deterioration in health.

The government's guidance states that aids and appliances in this context can include 'nomad trays' or similar and assistance can be help to physically open medication. The updated guidance states that nomad trays, pill boxes, alarms, reminders etc only apply if there is evidence they are needed due to your health condition and there is evidence to explain their use or if unable to read and need an aid to manage medication independently. No points scored if just used for convenience—so explain why they are needed.

Needles, glucose meters, inhalers and other equipment used to treat health at home are not aids according to the guidance. But if a spacer is needed to use the inhaler properly then argue that it is an aid or any equivalent extra equipment needed and any assistance/prompting/supervision needed to use or understand any equipment still counts.

In relation to needing help to manage therapy the government have stated that you do not have to actually receive therapy on the majority of days throughout a year but that you have need for the level of therapy specified in the descriptor assessed across the year. For example if you need help with dialysis at home one day a week every week, if that help is needed every week throughout the year and it is therefore needed on the majority of days. It is the length of time the supervision/prompting/assistance takes, not length of time the therapy takes that counts.

Remember that it is therapy at home, not at a healthcare professionals place of work that counts, therefore going for speech therapy sessions will not count *but* needing help to do any exercises or practicing recommended at home will.

Guidance says supervision to minimise risk of accidental or deliberate overdose or deliberate self-harm *has been* considered as a person requiring continuous support from another person to prevent this would fit into descriptor b and score 1 point. For Disability Living Allowance requiring continual supervision throughout the day to prevent deliberate self-harm met the criteria for an award of the middle care component—now you will receive 1 point albeit that the new requirement is continuous supervision for the activity and not throughout the day. Effectively the need for supervision to prevent harm has been down graded under the new test

# **Reliably: - Safely:**

- Risk of overdosing—accidental or deliberate.
- Taking too little medication, forgetting to take medication or not taking the correct medication at the right time.
- Failure to carry out therapy which is likely to lead to a significant deterioration of an individual's health condition as a result

# To an acceptable standard:

- Taking the medication or completing the recommended therapy, to avoid likely deterioration.
- Someone may be able to use an inhaler at the correct times, but not correctly so it is not as effective as it should be maybe not a risk to safety but not to required standard and so a need for prompting, supervision or assistance.

#### Q6 Washing and bathing

#### (i) Use page 8 of the Information Booklet

Please tell us about your ability to keep your body clean. This means things like:

- washing your body, limbs, face, underarms and hair, and
- using a normal bath or shower.

We want to know if you can do this safely, to an acceptable standard, as often as you need

to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

# Q6a Do you use an aid or appliance to wash and bathe yourself, including using a bath or shower?

Aids and appliances include things like:

• bath / shower seat, grab rails.



#### Q6b Do you need help from another person to wash and bathe?

Help includes someone:

- prompting, encouraging or reminding you to wash and bathe yourself or how to do it,
- supervising you to make sure you are safe, and
- physically washing or bathing you.

This includes help you have and help you need but don't get



# **Q6** Extra information - Washing and bathing

Tell us more information about the difficulties or help you need to keep your body clean. For example, tell us:

- If you cannot do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you are unable to do it at all.
- If you need help from another person, what kind of help you need (for example whether they need to encourage or remind you to wash and bathe or how to do it, supervise you to make sure you are safe or physically bathe you).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you have needs bathing just your lower or upper body, tell us which.
- If your ability to wash and bathe your body varies, tell us in what way and how often for example, telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness or tiredness.

If you put something in the box below you don't have to fill all of the box



4. Washing & Bathing	
a. Can wash and bathe unaided	0
b. Needs to use an aid or appliance to be able to wash or bathe	2
c. Needs supervision or prompting to be able to wash or bathe	2
d. Needs assistance to be able to wash either their hair or body below the waist	2
e. Needs assistance to be able to get in or out of a bath or shower	3
f. Needs assistance to be able to wash their body between the shoulders and waist	4
g. Cannot wash and bathe at all and needs another person to wash their entire body	8

The regulations give definitions:

Bathe: 'includes getting into or out of an un-adapted bath or shower'.

The current guidance for health professionals now states that descriptor E relates to a standard bath or shower. Therefore if you have an adapted bath or shower, but would need physical assistance to get in or out of a standard bath or shower this should apply instead of descriptor B for needing an aid or appliance, scoring 3 rather than 2 points.

The guidance for healthcare professionals gives examples of aids: long-handled sponge, shower seats and bath rails. A shower includes shower attachments for a bath.

The guidance states a wet-room is not considered an aid for this activity—therefore if you use a wet room as an adapted bath or shower is not sufficient for you to manage without assistance, use the guidance to argue that one of the higher scoring descriptors should apply.

The guidance comments that for descriptor d to apply you must be unable to make use of aids and cannot reach lower limbs or hair; therefore if it is reasonable for you • to use easily available aids and this would mean you could manage without physical assistance the lower scoring descriptor b would apply instead.

The guidance describes descriptor F as applying to any part of the body between the shoulders and waist, front or back.

Prompting may apply if you lack motivation or need to be reminded to wash.

If you have washed yourself but do not either realise you have failed to do so sufficiently or are physically unable to do so sufficiently and are still not clean this has not been done to an acceptable standard and therefore you should be considered unable to complete this activity.

This could apply to someone with learning difficulties, mental health problems or substance misuse problems or to someone with a visual impairment or just physically unable to complete the activity. It is important to explain why your health or disability means you cannot manage this to an acceptable standard.

**Reliably:** the guidance for healthcare professionals has given examples of how the issue of reliably affects the different activities: **Safely:** 

- Risk of falling or slipping causing injury (which descriptor may apply will depend on whether the activity can be managed safely by use of an aid such as a grab rail, or physical assistance or 'whether the risk of the adverse event is great enough to require continuous supervision for the duration of the task').
- Risk of drowning as a result of having a fit whilst bathing (this is no longer included as a safely concern in the current guidance).

### To an acceptable standard:

- The aim is that you are able to wash—clean and remove dirt/sweat and batheget in and out of a bath <u>or</u> shower.
- As well as doing the task will they be clean at the end (within a range of acceptability). The Oct 14 guidance states that 'clearly there is a range of acceptability when it comes to washing and bathing' but remember it has to be 'good enough' and therefore for this activity to be done to an acceptable standard you must be clean.

# In a reasonable time period:

- Someone who, has obsessive ideas around cleanliness and takes considerably prolonged periods of time to complete activities due to repetitive and extended hand washing.
- An individual who becomes breathless and exhausted whilst washing and dressing, and needs two hours to complete these tasks.

#### Q7 Managing toilet needs

#### (i) Use page 8 of the Information Booklet

Please tell us about your ability to go to the toilet and manage incontinence. Go to the toilet means:

- being able to get on and/or off a normal toilet, and
- cleaning yourself after using the toilet.

Manage incontinence means:

- • empty your bowel and bladder, including if you need a collecting device such as a bottle, bucket or catheter, and
- cleaning yourself after doing so.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q7a Do you use an aid or appliance to go to the toilet or manage incontinence?

Aids and appliances include things like:

• commodes, raised toilet seats, bottom wipers, bidets, incontinence pads or collective devices such as bottles, buckets or catheters.

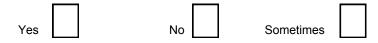
Yes	No	Sometimes	

# Q7b Do you need help from another person to go to the toilet or manage incontinence?

Help includes someone:

- prompting, encouraging or reminding you to go to the toilet or how to do so, and
- physically helping you to go to the toilet or clean yourself afterwards.

This includes help you have and help you need but don't get.



#### Q7 Extra information - Managing toilet needs

Tell us more information about the difficulties you have or help you need going to the

toilet and managing incontinence. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind of help you need (for example whether they need to remind you to go to the toilet or how to do so, or physically help you).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you are incontinent, tell us in what way and how well you manage this.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness or tiredness.

If you put something in the box below you don't have to fill all of the box.



5. Managing Toilet Needs or Incontinence	
a. Can manage toilet needs or incontinence unaided	0
b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence	2
c. Needs supervision or prompting to be able to manage toilet needs	2
d. Needs assistance to be able to manage toilet needs	4
e. Needs assistance to be able to manage incontinence of either bladder or bowel	6
f. Needs assistance to be able to manage incontinence of both bladder or bowel	8

Legal definitions:

**Toilet needs**: is defined as getting on and off an un-adapted toilet, evacuating the bladder and bowel and cleaning oneself afterwards.

**Manage incontinence**: is defined as manage involuntary evacuation of the bowel or bladder, including using a collecting device or self-catheterisation and clean oneself afterwards.

The government's guidance has stated that incontinence pads, raised toilet seats, bottom wipers, commodes or a stoma bag may count as suitable aids and appliances.

The HCP guidance states that 'indwelling (permanent) catheters or stoma are considered incontinent for the purposes of this activity' and does not include them on the list of aids but they are appliances as they 'are devices that provide or replace a missing function' - to score the higher scoring descriptors E and F you will need to explain what physical assistance is required to manage the incontinence. Because you count as incontinent you require more than assistance with toilet needs and descriptor D only refers to people needing physical assistance to get on/off the toilet and clean themselves, not help due to incontinence.

The guidance for healthcare professionals states that this activity does not include managing clothing as this is covered by activity 6, so the guidance says that if you only require help to get changed after suffering incontinence that this will not score points for this descriptor. However this is guidance only and is not law, the law in the regulations includes 'clean one-self afterwards', so you could argue that part of cleaning yourself afterwards is either prompting or physical assistance to change into clean clothes.

The HCP guidance now states that this activity also does **not** include climbing stairs or mobilising to the toilet. The guidance goes onto to say that if a commode is used just due to limited mobility to get to the toilet, instead of due to the risk of incontinence, it will not count as an aid to toilet needs because it is being used because of mobility problems instead and therefore not cover by this activity. A commode under this guidance will only score points if needed due to a bladder or bowel problem causing urgency. However a commode may be used due to a combination of mobility problems and problems controlling the bladder/bowel—if this is the case, focus on explaining the limited control problems.

But remember this is not the law and we advise to still include details of help you need getting to the toilet, if you cannot get to the toilet in time there is an argument that you cannot do this activity to an acceptable standard, including if you need to use a commode due to mobility problems. It could be argued that getting to the toilet is part of getting on the toilet.

We believe it can be argued that the ability to move around indoors is not covered anywhere in the test, especially as the guidance for the Moving Around activity refers to walking on outdoor surfaces—most toilets tend to be indoors.

Also include details of any help required to empty any aids such as a commode.

As all the activities look at your needs at any point during the day and night, you could argue that needing help to change bedding at night is part of needing help to clean yourself afterwards and to maintain a hygienic environment. Give details of all your problems with the activity, at this stage we do not know what will be accepted.

Give details of how problems such as substance misuse or mental health results in either not being aware or not being able to motivate yourself to clean yourself after having an accident and explain that this is due to your health problems.

**Reliably**, the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities:

# Safely:

- Slipping or falling when getting on or off the toilet.
- Sickness or infection due to an inability to maintain a hygienic environment.

# To an acceptable standard:

- The outcome for this activity is being able to evacuate the bladder and bowel (including using collecting devices) and clean oneself afterwards.
  - Where aids are used to manage incontinence, they must be appropriately and properly changed.

#### Q8 Dressing and undressing

#### (i) Use page 9 of the Information Booklet

Please tell us about your ability to dress or undress yourself. This means:

- putting on and taking off appropriate clothes, including shoes and socks,
- knowing when to put on or take off clothes, and
- being able to select clothes that are appropriate.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q8a Do you use an aid or appliance to dress or undress?

Aids and appliances include things like:

 $\cdot$  modified buttons, zips, front fastening bras, velcro fastening, shoe aids.

	Γ		
Yes	No	Sometimes	

#### Q8b Do you need help from another person to dress or undress?

Help includes someone:

- physically helping you,
- selecting clothes for you, and
- prompting or reminding you when to dress and undress or when to dress and undress or when to change into clean clothes.

This includes help you have and help you need but don't get

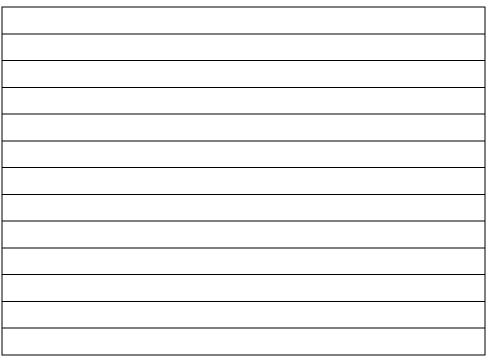


#### **Q8 Extra information - Dressing and undressing**

Tell us more information about the difficulties or help you need to dress or undress. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, what kind of help you need (for example whether they need to physically help you, select clothes for you or prompt you when to dress and undress, or when to change into clean clothes).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you only have difficulties dressing parts of your body, tell us which.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness or tiredness, tell us about these.

 $\cdot$  If you put something in the box below you don't have to fill all of the box.



6. Dressing & Undressing	
a. Can dress and undress unaided	0
b. Need to use an aid or appliance to be able to dress or undress	2
<ul> <li>c. Needs either:</li> <li>(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed or</li> <li>(ii) prompting or assistance to be able to select appropriate clothing</li> </ul>	2
d. Needs assistance to be able to dress or undress their lower body	2
e. Needs assistance to be able to dress or undress their upper body	4
f. Cannot dress or undress at all	8

Definitions—only one for this activity:

Dress and undress: includes putting on and taking off socks and shoes.

The government's guidance states this activity assesses the ability to put on and take • off 'culturally appropriate, un-adapted clothing that is suitable for the situation'.

The government have stated you would not be considered able to perform this activity reliably if you cannot determine when it is appropriate to change into clean clothes.

Although assistance is defined as physical assistance, if physical assistance is required to dress due to a cognitive impairment this should still count, for example due to a learning disability or brain damage you need more than reminding to get dressed but need someone to physically help you get dressed.

The guidance for healthcare professionals states the suitable aids include modified buttons, zips or trousers, front fastening bras, velcro fastenings or shoe aids. For this activity chairs or beds are not considered aids—however if you can only get dressed by sitting or lying down, it is likely to take you a lot longer to get dressed—

so can you do so in a reasonable time period? Explain how much longer it takes you on the form.

Consideration should be given to what clothing is appropriate for the environment such as time of day and the weather.

If due to conditions such as depression you regularly do not get dressed and stay in your pyjamas all day as it feels too much effort to get dressed because you feel too low, explain that you need prompting, even if you do not get it—make it clear this help is needed because of your mental health.

But if you do not get dressed because you physically cannot manage but do not have someone to help you everyday, explain why you cannot manage and what help you need.

For all activities it is the help you reasonably need in order to do the activity reliably that is important, not the help you actually receive.

**Reliably:** the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities:

### To an acceptable standard:

- The outcome in this activity is able to put on and take off un-adapted clothing [suitable for the situation and culturally appropriate].
- Is the clothing clean and appropriate for the weather conditions. Any failure must be due to a health condition or impairment, not personal choice.

# In a reasonable time period:

• An individual who becomes breathless and exhausted whilst washing and dressing, and needs two hours to complete these tasks will not have done this in a reasonable time period.

#### **Q9** Communicating

#### (i) Use page 9 of the Information Booklet

Please tell us about your ability to communicate with others. This means:

- speaking to people in your native vocal language, and
- hearing and understanding what people are saying to you in your native vocal language.

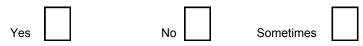
We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q9a Do you use an aid or appliance to communicate with others?

Aids and appliances include things like:

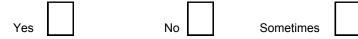
- hearing and voice aids,
- picture symbols, and
- assistive computer technology.



#### Q9b Do you need help from another person to communicate with others?

Help includes someone:

- prompting, motivating or encouraging you to communicate,
- interpret speech into sign into sign language for you, and
- tell you what someone is saying, what it means or speak on your behalf. This includes help you have and help you need but don't get.



#### Q9 Extra information - Communicating

Tell us more information about the difficulties or help you need to communicate with others. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you are unable to communicate at all.
- If you need help from another person, what kind of help you need (for example whether you need someone to prompt or encourage you to communicate, interpret speech into sign language for you or tell you what someone is saying or what it means).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you have difficulties with some communication but not others, tell us which.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain, breathlessness, tiredness or anxiety and distress.
- $\cdot$  If you put something in the box below you don't have to fill all of the box.



7. Communicating Verbally	
a. Can express and understand verbal information unaided	0
b. Needs to use an aid or appliance to be able to speak or hear	2
c. Needs communication support to be able to express or understand com- plex verbal information	4
d. Needs communication support to be able to express or understand basic verbal information	8
e. Cannot express or understand verbal information at all even with com- munication support	12

The regulations define:

**Basic verbal information**: Information in your native language conveyed verbally in a simple sentence.

**Complex verbal information**: Information in your native language conveyed verbally in either more than one sentence or one complicated sentence.

**Communication support**: Support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa.

This activity is both the ability to speak and to hear and understand what someone is saying to you.

The guidance has given examples of simple sentences: 'can I help you?', 'I would like tea please', 'I came home today', 'the time is 3 o'clock' and a complex sentence: 'I would like tea please; just a splash of milk and no sugar, as I always have sweeteners with me for when I go out'. Whether you agree that these are simple or complex sentences is a matter of judgement and open for debate.

The government's guidance explains that someone who is experienced in communication with people with specific communication needs includes both people well known to the claimant such as family, friends or support workers and people with experience of communicating with people with similar needs but who do not know the actual claimant.

Needing communication support still applies even if you do not have access to the support. The healthcare professional's guidance gives the example of a deaf person who cannot communicate verbally and does not use sign language possibly needing another person to write verbal information down even if they do not routinely have this help (remember if you rely on sign language an interpreter is communication support).

The government's guidance states that this descriptor may also apply to people who due to severe exhaustion, pronunciation problems or slurring are not reliably able to make themselves understood as they would not be considered able to verbally communicate to a necessary and appropriate standard.

The guidance for healthcare professionals says verbal information can include interpretation from verbal into non-verbal form and vice-versa, e.g. speech to sign language or written form. It also now states that the ability to lip read is not a consideration for this activity/

Examples given of an aid or appliance is a hearing aid or electrolarynx (but also consider the problems conveying verbally with an electrolarynx and the clarity of speech for the correct level of points).

The HCP guidance states that if you a not using a prescribed hearing aid, then the reasons why should be asked and if there is a 'good medical reason' such as chronic ear infections then hearing without the aid should be assessed, but if there is 'not a good reason' you should be assessed as if using the hearing aid.

Remember that the ability to understand is part of this descriptor, but because of the legal definition in the regulations defining what basic and complex verbal information is, it may be very difficult to include people with basic communication abilities in this activity. But the HCP guidance is trying to limit the scope further by stating the ability to remember and retain information is not part of this activity, giving the example of people with dementia or learning disabilities. We disagree with this– if you need support with understanding due to the level or type of learning difficulties or dementia, there is nothing in the regulations to prevent this.

**Reliably:** the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities:

### To an acceptable standard:

- The outcome is that an individual can understand spoken information and be understood themselves.
- Clarity of the claimant's speech should be considered. Having to concentrate a little harder e.g. articulating some sounds differently following a stroke but still being understandable would be an acceptable standard but would not be if you have to resort to gestures, writing it down or needing assistance in order to be readily understood.

The guidance states this activity applies 'when there are *physical difficulties* with communication' and the engaging with others activity covers interacting with people—again this is guidance only and if learning difficulties, cognitive or mental health problems prevent understanding, there is nothing in the current law that prevents this activity from applying and scoring points.

#### Q10 Reading

#### (i) Use page 10 of the Information Booklet

Please tell us about your ability to read and understand signs, symbols and words. This means signs, symbols and words written or printed in your native written language and doesn't include Braille.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

# Q10a Do you use an aid or appliance other than spectacles or contact lenses to read signs, symbols and words?

Aids and appliances include things like:

• · magnifiers.

		7	
Yes	No	Sometimes	

# Q10b Do you need help from another person to read or understand signs, symbols and words?

Help includes someone:

- ·reading for you, and
- • helping you to understand the meaning of signs, symbols or words.

This includes help you have and help you need but don't get.

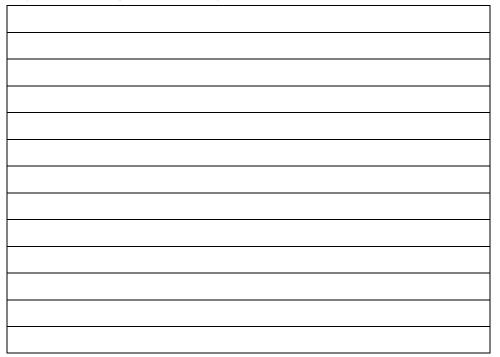
		] Γ	
Yes	No	Sometimes	

#### Q10 Extra information - Reading

Tell us more information about the difficulties or help you need to read and understand signs, symbols and words. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you are unable to read at all.
- If you need help from another person, what kind of help you need (for example whether you need someone to read for you or to explain to you what signs, symbols and words mean).
- If you use aids and appliances, tell us what type they are and how you use them.
- If your difficulties depend on how complicated the signs, symbols and words are, or how big they are, please tell us how.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity either during or after the activity like pain or tiredness.

· If you put something in the box below you don,t have to fill all of the box.



8. Reading & Understanding Signs, Symbols & Words	
a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses	0
b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information	2
c. Needs prompting to be able to read or understand complex written information	2
d. Needs prompting to be able to read or understand basic written information	4
e. Cannot read or understand signs, symbols or words at all	8

The legal definitions:

**Basic written information**: Means signs, symbols and dates written or printed in standard size text in your native language.

**Complex written information**: Is more than one sentence of written or printed standard size text in your native language.

**Read**: Includes reading signs, symbols and words but does not include reading Braille.

If you can only read Braille you cannot read, you must be able to see the information to be considered able to read.

The guidance states that this activity considers both the inability due to cognitive impairment to understand written information and the ability to visually see information.

The guidance states that the prompting descriptors may apply if you need another person to explain the information to you.

The guidance confirms that tactile and auditory methods, e.g. Braille will not be considered reading to take into account that this could involve expensive equipment or needing someone to help you access written information. However the use of aids such as a magnifier is counted and you would need to be totally reliant on Braille in order to score the higher points.

The healthcare professional's guidance states that consideration needs to be given to whether you can read and understand information both in and outdoors and uses an example of a large magnifier or blue screen to read text indoors and a portable magnifying glass outdoors. The previous guidance stated if you are unable to complete the descriptor either indoors or outdoors it may apply, therefore you should explain your difficulties in both situations. But the current guidance now states 'if despite aids the claimant cannot read both indoors <u>and</u> outdoors, another descriptor may apply'. This new guidance does not fit with the legal definition of **repeatedly**—'as often as the activity being assessed is reasonably required to be completed' and our advice is to explain the situations where you are unable to read information that you reasonably need to read, e.g. can read with equipment at home but not the bus times at the bus station which you need to see to get home from work.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities:

### To an acceptable standard:

- The outcome is that the individual can both read and understand the written information. Reading does not include Braille.
- While literacy will play a role, the activity only considers the individual's ability to read and understand basic and complex information as defined.
- e.g. if they can understand their bank statement or utility bill then this is acceptable as they can understand more than one sentence, even if they cannot understand newspapers and magazines.

The example of understanding bank statements or utility bills is a strange example as they are often difficult to understand, but if you have difficulty understanding your bills include this here. The example of complex written information give is: 'Your home may be at risk if you do not keep up repayments on your mortgage or any other debt secured on it. Subject to terms and conditions'.

The example of basic written information given is a green exit sign on a door, this is not legally correct as it would be written in very large text, whereas the legal definition given in the regulations is 'written or printed in **standard size** text', which most people would think of as 12 point.

To score points for this activity the guidance states that illiteracy must be caused by a health condition or impairment, for example learning difficulties, and not due to a lack of education, so it is important to explain the reason why you are unable to read or understand information. People can often have unrecognized learning difficulties though so think about school history, any extra help required etc.

#### Q11 Mixing with other people

#### (i) Use page 10 of the Information Booklet

Please tell us about your ability to mix with other people.

This means how well you are able to get on with other people, understand how they're behaving towards you and behave appropriately to them. It includes both people you know well and people you dont know.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

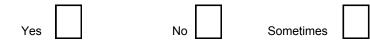
Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q11a Do you need another person to help you to mix with other people?

Help includes someone:

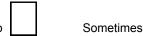
- prompting or encouraging you to do so,
- being there to support or reassure you, and
- helping you understand how people are behaving towards you.

This includes help you have and help you need but don't get.



Q11b Do you find it difficult to mix with other people because of severe anxiety



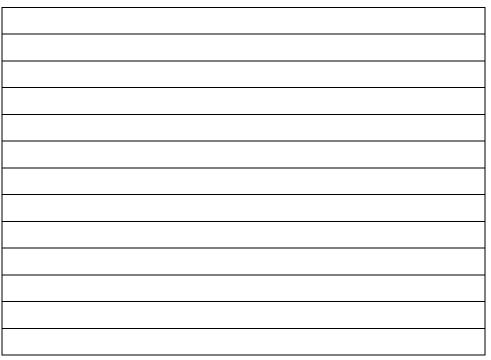


or distress?

#### Q11 Extra information - Mixing with other people

Tell us more information about the difficulties or help you need to interact with other people. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, what kind of help you need (for example whether you need them to prompt, encourage and support you or to help you understand how people are behaving and how to behave yourself).
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you avoid mixing with others, please tell us.
- If your ability depends on who you are mixing with, please give details.
- If you have side effects from carrying out the activity including before, during and after the activity like anxiety and distress or tiredness and fatigue.
- $\cdot$  If you put something in the box below you don't have to fill all of the box.



9. Engaging With Other People Face to Face	
a. Can engage with other people unaided	0
b. Needs prompting to be able to engage with other people	2
c. Needs social support to be able to engage with other people	4
<ul> <li>d. Cannot engage with other people due to such engagement causing either:</li> <li>(i) overwhelming psychological distress to the claimant or</li> <li>(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person</li> </ul>	8

The legal definitions again:

**Engage socially**: interaction with others in a contextually and socially appropriate manner, understand body language and establish relationships.

**Psychological distress**: distress related to an enduring mental health condition or an intellectual or cognitive impairment.

**Social support**: support from a person trained or experienced in assisting people to engage in social situations.

The government have said that this activity is about difficulties engaging with other people generally, not just people you know well and so have not confined the descriptors to specific situations. The activity considers your ability to interact with other people face to face in a contextually and socially appropriate manner, understand body language and establish relationships.

The previous guidance to healthcare professionals states that psychological distress may have a physical root cause. For descriptor D, the HCP guidance now refers to the legal definition resulting in 'a severe anxiety state in which the symptoms are so severe that the person is unable to function', citing conditions such as generalised anxiety disorder, panic disorder, dementia or agoraphobia.

Family and friends that know the person well will count as experienced in assisting people to engage in social situations as well as people who do not know them but are used to providing support to people with health conditions or impairments.

The first HCP guidance referred to needing the presence of a third party to interact with others for descriptor C, needing social support. The July 15 guidance now states that this descriptor 'may apply to people who can only engage with others with active and skilled support on the majority of days, or who are left vulnerable

due to their level of risk-awareness as a result of their condition'. It may help to describe what the person giving support is doing i.e. providing reassurance, explaining how to behave, monitoring for inappropriate behaviour etc.

The HCP guidance for B has changed back to may apply to people 'who need encouragement to interact with others by the presence of a third party'. Legally prompting does not have to happen through the duration of an activity and therefore if someone just needs prompting to start engaging in social contact, then they should still explain this.

The inability to engage socially must be as a result of your health condition or impairment and not 'simply a matter of preference by the claimant'. Therefore if you are unable to engage socially due to your mental health, such as due to your level of anxiety or because of problems establishing relationships with people because of being on the autistic spectrum, explain both the problems and the cause of the problems.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities: **Safely:** 

• Becoming violent which presents a serious risk of harm to the claimant and/or another person.

### To an acceptable standard:

- The outcome is that they can engage with other people face to face in a contextually and socially appropriate manner, understand body language and establish relationships.
- Simple shyness and reticence are not unusual. However an individual who always suffers severe anxiety or panic attacks when engaging with other people, even with support, cannot complete the activity at that level to an acceptable standard.

Use examples of any incidents that have happened when your mental health or cognitive impairment have resulted in being unable to control your temper leading to aggressive behaviour to others. Although the guidance states becoming violent as a safely concern – also consider that verbal aggression and/or disinhibited behavior can also be a safety risk. This behaviour must be due to your health.

Explain how often you have cancelled appointments because on that day your level of anxiety or paranoia was too high for you to cope engaging with other people. Remember this does not have to be everyday, a descriptor applies if it applies for over 50% of the days in a year.

#### Q12 Making decisions about money

#### (i) Use page 10 of the Information Booklet

Please tell us about your ability to make decisions about spending and managing your money.

We want to know whether you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

# Q12a Do you need someone else to help you to understand how much things cost when you buy them or how much change you'll receive?

Help includes someone:

- encouraging you,
- reminding you to do it or how to do it, and
- doing it for you.

This includes help you have and help you need but don't get.

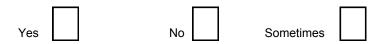


# Q12b Do you need someone else to help you to manage your household budgets, pay bills or plan future purchases?

Help includes someone:

- encouraging you,
- reminding you to do it or how to do it, and
- doing it for you.

This includes help you have and help you need but dont get.



#### Q12 Extra information - Making decisions about money

Tell us more information about the difficulties or help you need making decisions about spending and managing your money. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind of help you need (for example whether they need to remind you to do it or how to do it or do it for you).
- If you can do it but it takes you a long time.
- If your needs vary, tell us in what way and how often for example telling us about good days and bad days or how it varies throughout the day.
- If you have side effects from carrying out the activity including before, during and after the activity like significant anxiety and distress.

If you put something in the box below you don't have to fill all of the box

-	

10. Making Budgeting Decisions	
a. Can manage complex budgeting decisions unaided	0
b. Needs prompting or assistance to be able to make complex budgeting decisions	2
c. Needs prompting or assistance to be able to make simple budgeting decisions	4
d. Cannot make any budgeting decisions at all	6

The legal definitions:

**Simple budgeting decisions**: decisions involving calculating the cost of goods and calculating the change required after a purchase.

**Complex budgeting decisions**: decisions involving calculating household and personal budgets, managing and paying bills and planning future purchases.

The government's guidance states that this activity focuses on mental, cognitive and decision making ability and not physical or sensory impairments and states that assistance in this activity refers to another person carrying out elements, although not all, of the decision making process for you.

BUT the legal definition of assistance is 'physical intervention by another person and does not include speech', therefore if you need physical help with this activity i.e. assistance, then legally it applies. E.g. a blind person may need the physical intervention of someone in order to see their change in a shop or to see the amount on a bill in order to make a decision. The guidance is not the same as the law and should not conflict with the law, so explain any physical help needed to make a budgeting decision here *and be prepared to argue the case*.

Prompting has been described as the claimant needing to be encouraged or reminded to make budgeting decisions.

The HCP guidance describes B as applying to people who need assistance managing their household bills or planning future purchases. A claimant who is vulnerable due to cognitive or developmental impairments and is vulnerable due to not understanding 'everyday financial matters' should be considered.

The previous HCP guidance stated that in order to complete this activity, claimants do not need in-depth financial knowledge. Complex budgeting decisions are those that are involved in calculating household and personal budgets, managing bills and planning future purchases. It does not include decisions which require financial knowledge, e.g. calculating interest rates or comparing mortgages.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities:

# To an acceptable standard:

- The outcome is being able to make budgeting decisions.
- Not whether a good decision has been made, but that you understand the decision made e.g. understand need to pay bills and budget but make an expensive purchase despite this, even though you know you have bills to pay and understand how to budget. *But* if bad decisions are made consideration should be given to whether this is due to a health condition or impairment.
- Lack of motivation should again be considered as to whether this is due to a health condition and the guidance states consideration must be given to 'whether the individual would carry out the activity if they really had to' e.g. a final notice.

If due to mental health conditions, such as manic depression, you lose control of your decision making ability when in a manic or 'high' phase and spend all of your money with no thought of the consequences, then explain this here and explain any patterns of this behaviour.

If you suffer from a substance dependency and are fully aware that you cannot afford your dependency, but are unable not to spend your money on your addiction despite knowing the consequences, argue that this should count because you have made the bad decision as a result of your health condition.

# Mobility

#### Q13 Going out

### (i) Use page 11 of the Information Booklet

Please tell us about your ability to work out and follow a route to another place and if severe anxiety or stress prevents you from going out. A route includes using public transport.

This activity doesn't look at your physical ability to get around which is covered in Q14 Moving around.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

Q13a Do you need help from another person to plan a route to somewhere you know well? Or do you need another person, guide dog or specialist aid to help you get there?

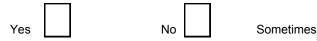
Help includes someone:

- to help you plan a route or plan it for you,
- to prompt or encourage you to go out or be with you when going out to reassure you, and
- to be with you to keep you safe or stop you getting lost.

#### Aids include:

• long canes and white sticks.

This includes help you have and help you need but don't get.



# Q13b Do you need help from another person, guide dog or specialist aid to get to a location that is unfamiliar to you?

Help includes someone:

- to prompt or encourage youto go out or be with you when going out to reassure you,
- to be with you to keep you safe or stop you getting lost, and
- to help you deal with public transport or unexpected circumstances. Aids include:
- · long canes and white sticks.

This includes help you have and help you need but don't get.



# Q13c Are you unable to go out because of severe anxiety or dis-

\_\_\_\_\_No \_\_\_\_

#### Q13 Extra information - Going out

Yes

Tell us more information about the difficulties or help you need to work out and follow a route to another place and whether severe anxiety or stress prevents you from going out. For example, tell us:

Sometimes

tress?

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind of help you need (for example whether they need to plan a route for you, encourage you to go out, reassure you or help you to make sure you don't go the wrong way).
- If you use a specialist aid such as a long cane or white stick, please tell us.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If your needs vary depending on where youre going, or what the route might involve, please tell us.
- If you have side effects from carrying out the activity including before, during and after the activity - like anxiety and distress.

If you put something in the box below you don't have to fill all of the box

1. Planning and Following Journeys	
a. Can plan and follow the route of a journey unaided	0
b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant	4
c. Cannot plan the route of a journey	8
d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid	10
e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant	10
f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid	12

The regulations define:

**Psychological distress**: as distress related to an enduring mental health condition or an intellectual or cognitive impairment.

Assistance dog: a dog trained to guide or assist a person with a sensory impairment, which means guide, hearing and dual sensory dogs.

**Orientation aid**: a specialist aid designed to assist disabled people to follow a route safely. (The guidance explains that a specialist satellite navigation system will count as an orientation aid, but that a generic sat. nav. will not).

The guidance states that 'journey' means a local journey, whether familiar or unfamiliar, and that environmental factors count., e.g; being unable to reliably complete this activity because you are unable to cope with crowds or loud noises.

Both the Oct 14 and July 15 HCP guidance contain significant changes and makes a clear separation of the types of impairment that the descriptors cover, this has started to be tested in caselaw and you should continue to explain how you believe you meet the wording of the descriptor in line with the regulations and remember guidance is not law.

Despite the new guidance, it is important for people who due to anxiety or depression are unable to go anywhere unfamiliar but can manage familiar routes to focus on why they cannot follow an unfamiliar route specifically rather than focussing on the psychological distress of going out alone which impacts on their ability to undertake all routes.

The HCP guidance describes 'overwhelming psychological distress' as meaning 'a severe anxiety state in which the symptoms are so severe that the person is unable to function', as could occur with agoraphobia, generalised anxiety state or panic disorder.

For descriptor B the guidance now says it applies when going out causes overwhelming psychological distress and prompting is needed on the majority of days to go out. The prompting can take place before or during the journey and 'any journey' means any

single journey' on the majority of days. If with support you can successfully make a journey the majority of days then B is likely to apply. If agoraphobia is severe & on the majority of days you're unable to go out even with support, then E is more appropriate.

The important legal point about descriptors B and E is that they refer to any journey– not just familiar local journeys, so the guidance says if you can take your child to school they do not apply. But remember the descriptor only has to apply on over 50% of days in a year—so if you can go out on a good day there is no reason why it should not apply—explain the proportion of good/bad days.

The guidance states that B could also apply if you are actively suicidal or at risk of exhibiting violent behaviour and require prompting when out not to harm yourself or others. The HCP guidance states there 'must be good evidence the person is a suicide risk', such as the involvement of mental health services, a care plan etc. For violent behaviour the guidance says good evidence of being unable to control behaviour is required and that being prompted 'reduces a substantial risk of the person committing a violent act'. If due to disinhibition or lack of awareness of risk supervision or support are required to follow a journey safely then D or F should be argued—answer using terms such as 'I am unable to safely follow the journey reliably without assistance from another person because......'

The Oct 14 guidance said that C, D and F are unlikely to apply to mental or behavioural disorders and has now been taken out of the July 15 guidance, so do not limit these descriptors as only applying to cognitive, sensory or developmental problems which the guidance still says they are most likely to apply to and there is nothing in the law to prevent it.

Guidance claims that C applies to people who due to cognitive or developmental impairments (used to be sensory instead of developmental) cannot plan a journey using maps, phone apps or timetables but could follow a route planned by someone else on their own and ask for help if the 'bus is diverted', if this applies consider whether you could realistically and reliably cope with unexpected changes and whether help to follow a journey is more appropriate.

D and F are described in the guidance as applying to people with cognitive, sensory or developmental impairments who cannot work out where to go, follow directions or deal with unexpected changes. 'Follow' is described as meaning to 'the visual, cognitive and intellectual ability to reliably navigate a route' and that any accompanying person should be 'actively navigating' for the descriptors to apply, not if they are there for any other reason—this is not a meaning defined in the legal regulations.

The guidance says that needing assistance to deal with unexpected changes to a journey, e.g. roadworks or changed bus stops, should be taken into account when assessing whether someone can follow a journey reliably and whether this prevent you from completing the journey. The guidance also states you should only be considered able to follow an unfamiliar journey if you are capable of using public transport out of ability rather than choice.

# NB: Continued on the last page of this guide

#### Q14 Moving around

#### (i) Use page 11 of the Information Booklet

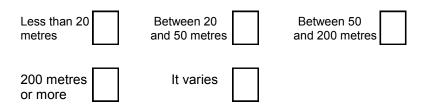
Please tell us about your ability to physically move around.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

#### Q14a How far can you walk taking into account any aids you use?

• • • to give you an idea of distance, 50 metres is approximately 5 buses parked end to end.



#### Q14b Do you use an aid or appliance to walk?

Walking aids include:

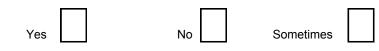
- walking sticks,
- walking frames,
- crutches, and
- prostheses.





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Q14c Do you use a wheelchair or similar device to move around safely, reliably and repeatedly and in a reasonable time period?



#### Q14 Extra information - Moving around

Tell us more information about the difficulties or help you need to physically move around. For example, tell us:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you regularly fall or are at risk of falling.
- If you use aids to help you walk, tell us what type they are for example walking sticks, crutches or a prosthesis and how you need to use them.
- If you use a wheelchair or similar device, tell us whether its manual or powered and how often you need to use it.
- If your needs are affected by the terrain, please tell us for example whether you have difficulty with uneven ground, curbs or steps.
- If your needs vary, tell us in what way and how often for example telling us about good and bad days or how it varies throughout the day.
- If you have side effects from carrying out the activity, like pain, breathlessness, tiredness, dizziness stress or anxiety either during or after the activity tell us about these.
- If you can do it but it takes you a long time.

If you put something in the box below you don't have to fill all of the box.



2. Moving Around	
a. Can stand and then move more than 200 metres, either aided or unaided	0
b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided	4
c. Can stand and then move unaided more than 20 metres but no more than 50 metres	8
d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres	10
e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided	12
f. Cannot, either aided or unaided:	12
(i) stand <b>or</b> (ii) move more than 1 metre	

Legal definition:

**Stand**: is defined in the regulations as meaning stand upright with at least one biological foot on the ground.

Therefore a double amputee cannot stand and should be awarded descriptor f, but a single lower limb amputee may be able to stand, a prosthesis is considered to be an appliance in the guidance and therefore you will have to consider how far you can reliably move.

Move is not defined in the regulations but the guidance for healthcare professionals clarifies that this activity requires a person to stand and then move independently while remaining standing. If a wheelchair is needed to move that distance you should be considered not to be able to stand and move the distance.

The government's guidance states that issues such as breathlessness, pain and fatigue should be taken into account in whether this activity can be done reliably and if you are unable to complete this distance because of these factors or other symptoms then the appropriate descriptor should be given.

The guidance for healthcare professionals states if you can walk a distance but would be unable to repeat it again that day, this is not repeatedly and therefore the activity has not been reliably completed.

The guidance for healthcare professionals states this activity should be judged in

relation to flat outdoor surfaces including kerbs.

The 20 metre distance is considered the distance to achieve a basic level of independence in the home, 50 metres to achieve a basic level of independence outdoors and 200 metres a higher level of independence outdoors.

Aids and appliances may include walking sticks, crutches and prostheses.

The healthcare professional's guidance says in order to do this activity reliably consideration should be given to the manner of moving, including gait, speed, risk of falls, symptoms or side effects such as pain, breathlessness and fatigue.

The HCP guidance states that this activity is only the physical act of moving and awareness of danger is considered under activity 11, Planning and Following Journeys. However there is some overlap in the case of falls and there will remain issues surrounding people suffering from conditions such as autism who may refuse to walk and ground themselves and therefore are unable to manage the physical act of walking.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliability affects the different activities: **Safely**:

• Risk of falling

# To an acceptable standard:

• In order to complete this activity to an acceptable standard the claimant should be able to move the distance in an upright position.

# **Repeatedly:**

- A person who is able to stand and move 20 metres unaided, but is unable to repeat it again that day cannot do it repeatedly as you would reasonably expect people to move 20 metres more than once a day.
- If a person can walk one day, but the exertion means they are unable to the next this should be considered. Longer periods of fluctuating ability should be looked at in relation to the rules on fluctuating conditions (see front page of this guide.
  - 'symptoms such as pain, fatigue and breathlessness should be considered when determining whether an activity can be carried out repeatedly. Whilst these symptoms may not necessarily stop the claimant carrying out the activity in the first instance, they may be an indication that it cannot be done as often as is required'.

#### **Q15 Additional Information**

Tell us anything else you think we should know about your health conditions or disabilities and how these affect you that you haven't mentioned already.

- If any carers, friends or family want to provide further information they can do so here.
- You don't have to complete this part if you've covered everything in the form.

If you put something in the box below you don't have to fill all of the box.

Continue on separate pieces of paper, if needed. Remember to write your name and National Insurance Number at the top of each page and tell us which questions your comments refer to.

#### What to do now

#### **(i)** Use page 11 of the Information Booklet

Check you've filled in all questions that apply to you or the person the claim is for and sign the declaration below in ink. Tear off the letter on the front page; you don't need to send this back. On the last page you will see the address to return this form. Place this form in the envelope provided so that the address shows through the window. It doesn't need a stamp.

#### What happens next

#### (i) Use page 12 of the Information Booklet

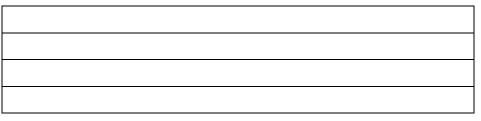
You're likely to be contacted soon to arrange a face to face consultation with a health professional. You'll be able to take someone with you to this.

If we've enough information already, a consultation may not be needed. Tell us about any help you (or someone who may accompany you) would need if you have to go for a face to face consultation.

This will help us ensure your needs are met or consider if a home visit would be needed. For example tell us if:

- you / they can't get up and down stairs,
- you / they have difficulty travelling or using public transport,
- you / they have communication needs and what support you / they will need, and
- you / they need accessible toilets.

Please be specific about the needs you / they have.



**Face to Face Consultation:** A healthcare professional will assess which of the 'daily living' and 'mobility' descriptors apply.

This will be very similar to an Employment and Support Allowance medical although the descriptors are different. Claimants can take someone with them to this assessment.

Capita who will be responsible for arranging the assessments in Wales have said that a large number of the consultations will take place in the claimant's home. The regulations allow for this consultation to also take place by phone.

The guidance for healthcare professional's states they should read all the evidence on file prior to the consultation, therefore it is important to ensure that any supportive evidence available is supplied before this stage. At the consultation a clinical history of all conditions should be taken, because of how the point scoring system works it is important that the healthcare professional is informed of all of your problems, not just what you view as your main problem. The healthcare professional should record your 'relevant social and occupational history' and will ask questions about your 'typical day' in order to establish how your health/ disability affects your daily living and mobility. Informal observations will be made as part of the assessment e.g. your appearance, manner, ability to walk into the assessment room etc. If relevant according to your health/disability clinical examinations may be done to establish problems with mental function, sensory impairment, cardiorespiratory, musculoskeletal and nervous or other body systems.

Following the consultation the healthcare professional will produce a report to be sent to the DWP. In the report the healthcare professional will choose which descriptor they believe reflects the claimant's ability in each activity and what their likely prognosis is which will advise the decision maker on the level and length of any award. The guidance for healthcare professionals states they should not consider whether the descriptors chosen will lead to entitlement to payment of PIP but only whether the descriptor is appropriate. Whilst the decision maker can come to a different conclusion based on the evidence from the healthcare professional, the experience of the Work Capability Assessment leads us to believe the decision maker will usually accept the healthcare professional's opinion.

### **Planning and Following Journeys continued:**

In a change from the rules for DLA if someone suffering from conditions such as severe agoraphobia causing 'overwhelming psychological distress' is unable to leave their house at all, the guidance states they can still qualify for the standard mobility component. The HCP guidance states that if even with prompting you are unable to go out most days, then descriptor E will apply.

**Reliably**: the guidance for healthcare professionals has given examples of how the issue of reliability affects Planning and Following Journeys: **Safely:** 

# Injury as a result of being unaware of obstacles, e.g. due to visual impairment.

- Lacking a perception of danger presenting risk of injury to themselves or others, e.g. running into the road.
- Getting into an unsafe situation as a result of getting lost due to a health condition or impairment and being unable to resolve being lost.

### To an acceptable standard:

•

- The outcome is able to work out how to get somewhere and then follow that route for either a familiar or unfamiliar journey.
- Is claimant likely to get lost? Many would get a bit lost in unfamiliar places but most are able to recover. Getting excessively lost, or be unable to recover their bearings is not following a journey to an acceptable standard.

**Caselaw:** At the time of writing 2 pieces of caselaw have been decided for this activity—both cases are at the same level of law and therefore have equal weight, but come to very different conclusions as to when the descriptors can apply.

*UK/622/2015 [2015] UKUT 344 (ACC)* broadly supports the view given in the HCP guidance and states that descriptors d and f '*are limited to one aspect of the journey, following its route*' and '*envisages a person who is helping the claimant to follow the route*' as opposed from the distress of going on a journey.

*CSPIP/109/2015 [2015] UKUT 386 (ACC)* supports a much wider view of descriptors d and f and that it 'covers the situation where a claimant 'cannot follow'' the route because they cannot navigate the route or because they cannot follow it because of some psychological factor, such as anxiety, even if they have the intellectual capacity to follow the route in theory'. The Judge goes on to state that unlike in the case of an assistance dog or orientation aid 'there is no definition limiting the purpose for which the person can be used' and this need for another person to enable the claimant to follow the route 'can be any reason including a mental health reason such as overcoming anxiety or other psychological distress'.