

## PIP APPLICATION –

### How your disability affects you

#### Section 2

##### Q2a

Health Condition or disability	Approximate start date
Sickle cell disease	From birth
Acute coronary syndrome	2005
TIA / Stroke	2004
Bilateral hip necrosis	2005
Bilateral shoulder necrosis	2012
Obstructive Sleep Apnoea	2015
Angina	2005
IBS	2012
Meniscus tear – right knee	2014
Cognitive impairment	2012
Fibroids	2015
Breathlessness	2005
Fatigue	2005
Blackout, since stroke	2004
Falls	2004

##### Q2b

Medications	Side Effects
Hydroxycarbamide 1.5g cytotoxic drug once daily at night	Nausea, vomiting, itchy red skin, hot sweats, diarrhoea, shivering, low platelets, low white counts, rash, wheezing, breathlessness, sore throat, numbness, cramps, nose bleeds, weakness
Hydromorphone 8mg (Morphine) twice daily	Dizziness, vomiting, dry mouth, hot/cold sweats, urine

	retention with pain in abdomen, blurred vision, drowsiness, itching, sweating, urine retention
Bisoprolol 10mg twice daily	Headaches, dizziness, faintness, dry mouth, tiredness, weakness, anxiety, spinning sensation, diarrhoea, ringing in my ears,
Enalapril 5mg	Coughing, nausea, dizziness, loss of taste, loss of appetite, low mood, itching,
Simvastatin 40mg daily at night	Muscle pain, tenderness, weakness, fatigue, confused, memory problems, forgetfulness, palpitations,
Apixaban 5mg twice daily	Nose bleed, gum bleeds, bruises, heavy painful periods, vomiting, dark stools, fecal incontinence
Furosemide 20mg twice daily	Itching, loss of appetite, severe pain in abdomen especially with eating, nausea, vomiting, ringing in ear, fecal incontinence
Amitriptyline 20mg at night	Headaches, confusion, numbness, weakness in arms and legs, blurred of vision, skin rash, swelling of your face and tongue, nausea, vomiting
Tramadol 50mg twice daily	pruritus, agitation, anxiety, constipation, diarrhoea, hallucination, nausea, tremor, vomiting,
Cocodamol 30/500mg up to four times daily	Alternating constipation and diarrhoea, nausea, vomiting, dizziness, urine retention, bladder pain
Amlodopine 10mg twice daily	swelling of legs or ankles,

	tiredness or extreme sleepiness, stomach pain, nausea, dizziness, flushing on face], irregular heart beat palpitations
Folic Acid 5mg	Nausea, bloating, poor appetite, anxiety, low mood, lack of taste
GTN Spray (glyceryl trinitrate spray)	Dizziness and fainting, especially on standing, precipitates my angina, blackout, headaches, low blood pressure, blurry vision, muscle pain
Aspirin 75mg at night	Vomiting, stomach pain, heartburn, drowsiness, nausea
Home CPAP machine	Claustrophobic, nasal congestion, sore eyes, headaches, dry mouth, boating in abdomen, very noisy
TENA machine for pain relief – nerve stimulator machine	Muscle twitching, tingling sensation, skin irritation,
Co-Amoxiclav 500/125 twice daily	Diarrhoea, stomach pain, nausea, vomiting, skin rash, itching, vagina discharge/yeast, swelling of face, numbness,
Lansaprazole 15mg twice daily	Dizziness, confusion, fast heartbeat, palpitations, feeling jittery, muscle jerks, restless legs, choking sensation, fits
Ispaghula Husk one sachet twice daily	Stomach pain, diarrhoea, dizziness, chest pain, vomiting,
Salbutamol inhaler two puffs as needed	Nervousness, shaking, palpitations, headaches, dry mouth, cough, hoarseness, tremor, sore throat
Adcal D3	Stomach ache, alternating

	diarrhoea and constipation, skin rash, stomach upset and pain, vomiting, feeling sick
Chlorpheniramine 4mg every four to six hours	Dizziness, drowsiness, blurry vision, nervousness, dry mouth, nose, and eyes, decrease coordination,
Lidocaine Patches daily two patches	Blurred vision, chest pain and discomfort, cold, clammy, flushes, confusion, feeling dizzy, faintness
Clobetasone cream	Burning, twitching of the skin, irritation,
E45 Cream	Burning sensation, itching, erythema, pus on skin
<b>Homeopathic medications:</b> Calc Carbonicum, Causticum, Ferrum Phosphoricum 30c, Arnica & Ruta cream, Lachesis 30c, Opium 30c, Bryonia 30c, Digitalis 200c, Calendula cream	No side effects
Acupuncture for back pain	2016

### Question 3

#### Preparing and cooking food

Q3a Yes

Q3b Yes

#### Q3c Extra information – Preparing food

- I cannot stand for long period to cook because of pain in my hip and back and legs. I have avascular necrosis of both hips and shoulder and arthritis in elbow. I have meniscus tear in right knee that is painful to stand.
- I get pain in my hands, fingers, shoulder, elbows.
- Also due to my memory and sleep problem I forget things on fire even while sitting there. I always feel tired and dizzy due to severe anaemia and the side effects of pain medication. I cannot chop or peel anything due to pain in whole arms.
- At the moment my daughter does most of the cooking at weekends for the whole week.

- I cannot prepare or cook meal myself at all. I have been banned from cooking for health and safety reasons. I have left things on the cooker and slept off or I totally forgot and neighbour saw the smoke and called the ambulance to break in and they saw me sleeping in the smoke. I cannot manage to cook at all hence I do not get to eat the fresh food I need until weekend when my daughter is around.
- I am not allowed to operate the cooker or oven at all for my safety and others
- I cannot bend my back or knee to use the oven too; it's too painful and I get dizzy due to the number of medications I take. The oven tray is too heavy for me to lift so I cannot lift it. I have a kitchen stool to sit and watch my daughter cook for me at weekends. I am in too much pain to go through the process.
- **Help from another person:** I need someone to cook the meal, cut, chops onion or fruits, or tomatoes or meat or fish as I cannot do this due to pain in my fingers and the whole of my hands.
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#### **Question 4: Eating and drinking:**

4a: Yes

4b No

4c Yes

#### **4d Extra Information – Eating and drinking**

- Due to my IBS, I get pain in my stomach and back when eating so I need to be prompted regularly to eat as I am always afraid of eating. I also tend to forget to eat; I don't feel hungry. I don't feel motivated to eat. I can't use knife to cut meat or steak due to pain in hands and fingers and poor grip.
- My kitchen is downstairs and I find managing stairs painful to get the food. I need help to warm food and hot water to drink and it's so painful to eat. I eat in small portions, several times.
- It's the same anytime I eat I get pain in upper stomach radiating to my back.
- I get nausea and clammy while eating and I have to stick my finger in my throat to bring out the food to ease the pain. It takes me about an hour to finish eating as I have to eat slowly.
- I only use lightweight plastic forks and spoons and plastic cups due to poor grip and pain; these are not heavy. I need someone to cut up the food and also to help me clean the vomit. I need someone to help massage my back to ease pain while eating

#### **Question 5 Managing treatment**

Q5a Yes

Q5b Yes

#### **Q5c Extra information – Managing treatment**

- I am in too much pain that I cannot concentrate on the instructions and on what to take. I tend to take too much just to ease the pain if I am not monitored. I forget what I have already taken and lose sense of time when to take the next one. I take too much if not monitored. I don't understand the instructions or recommendation. I need supervision and prompting to take my treatment as it's just too overwhelming for me.
- I use dosette box to remember. My daughter arranges the medication for me. I need hot water bottle to help with pain. My pain aggravates if I don't get to take the medications on time. I need help to massage in heat balm on my body. I cannot touch the cytotoxic drugs with my bare hands; I need to wear gloves to take this.
- It can take me 35 to 45 minutes to do my medication each time as I get confused what to take and need hot water to take it. It's the same routine throughout the day.
- I get nausea and vomiting. I get breathless and anxiety. I get palpitation with hot sweats or clammy. I also itch with the medication and loose running stool. I get incontinence of urine. I use Tena pads.
- I need help to monitor what I am taking and not to take too much. I need help with boiling water to drink it with. I need help to clean my vomit and stool. I need help with scratching my body when itching. I need help to apply the heat pad or the Lidocaine patches to my back and shoulders. I feel drowsy on eating. I need help with filling the hot water bottle as I have dropped it due to poor grip and pour hot water on myself in the past.

## **Question 6 Washing and bathing**

Q6a Yes

Q6b Yes

### **Q6c Extra information – Washing and bathing.**

- I need help to wash or bath due to pain in my hips (AVN hips), lower back and legs and I have AVN in shoulders. I cannot lift up my legs to get in the bath. I feel dizzy and black out when bathing and getting in and out of the bath. I need to hold on to someone for assistance not to fall. I need prompting to bath due to my pain; I get anxious thinking about it.
- I only have showers on weekends when I have my daughter to help me. I have a stool to climb in and a bath seat to sit on in the shower as I cannot stand. I only wipe down my front part when no one is around to help me. I can only use a single lever tap due to pain in my elbows, hands and arms.
- It takes me about 30 to 45 minutes to wash and bath when I get help.
- It's difficult to move my hands around due to pain in elbow (arthritis of the elbow). I cannot reach my back, buttocks and backside. I cannot bend to wash my legs. I cannot raise my hands to wash my head or hair due to pain in my shoulders. I blackout in the shower and fall so I need supervision to do this.
- I always have aggravation of my back and hip pain and shoulder after this activity. I feel tired and fatigued; I get anxious before starting the activity as I am afraid to shower.

### **Question 7 Managing toilet needs**

Q7a Yes

Q7b Yes

#### **Q7c Extra information – Managing toilet needs**

- Due to pain in my back and hips I cannot sit down on a standard toilet seat; it's too low for me. I cannot get up from a low toilet seat due to pain in back, knees and hips. I cannot bend my knees to seat too low due to meniscus tear in knee and severe pain. I get alternating diarrhoea and constipation so it's very painful passing stools. I can vomit at the same time as passing hard stools.
- I use a raised toilet seat on my toilet, permanently. I wear Tena pants for urine incontinence.
- It takes me about 30 to 45 minutes each time as I have to take my time to do this. I get urine retention due to some medication I take so it takes longer for urine to come out and I need to use catheter to empty my urine.
- I get pain in my back and abdomen and a pulling pain in my thigh while doing this and afterwards. I get palpitations and chest pain and feel weak and tired.
- I need help with cleaning my vomit and my backside after passing stool, as I cannot control my diarrhoea. After sitting for a long time I need help with getting up straight again.

### **Question 8 Dressing and Undressing**

Q8a YES

Q8b YES

#### **Q8c - Extra Information Dressing and undressing**

- I have difficulty dressing the upper part of my body because I cannot raise my hands to put on my dress alone or take my dress off due to pain in my shoulders; I have AVN to both shoulders and had a surgery to the left shoulder which has not helped the pain or movement and my orthopaedic surgeon has recommended total replacement surgery to both shoulders. I cannot bend my lower parts to wear my knickers or trouser or shoes due to necrosis of my hips. I cannot do my bra at the back due to pain. I cannot zip dresses at the back due to painful hands and arms. I get dizzy spells bending down. I cannot cream my upper and lower body or back due to pain and restrictions. I need to wear multiple clothes to keep warm and I need help choosing appropriate clothes to wear

- My daughter helps me to dress when she is home. She chooses suitable warm clothes for me. I do not wear knickers or trousers when no one is there to help. I can only wear slip on shoes. I cannot wear shoes with laces or buckles as I cannot bend down to do them. I do not wear bras most days. I use long shoe horn to slip my shoes on as I cannot bend down to do it.
- It can take up to 30 to 45 minutes to get dressed as I struggle a lot without help and I wait for my daughter to get home before I undress.
- After each activity I get breathless and increased pain. I get palpitations and headaches due to exertion.

### **Question 9 Communicating**

Q9a No

Q9b Yes

### **Q9c Extra Information – Communicating**

- Due to the number of medication I take, I get confused when communicating with people and people cannot hear me because my speech falters. I lose track of sentences and communication and cannot understand what people say to me. I get brain fog due to the level of my pain.
- My daughter helps me out and explains what people say to me. Even at work my colleagues helps me and my employers are very understanding of my disability and I have some adjustment to the way I work; I take my time to do things.
- I need support communication in complex situation or in midst of people
- I am always fatigued and anxious due to my pain and anxiety. I get palpitation and chest pain when I cannot express myself clearly and embarrassed when people cannot understand me. I get exerted and this triggers my angina.

### **Question 10 - Reading**

Q10a No

Q10b Yes

### **Q10c Extra information - Reading**

- I am always in pain; I am never pain free and also due to my memory impairment I get confused understanding what I read. I cannot just process it. I find it difficult reading complex written information; it's too difficult for me. I need someone to help me understand. I have to read over and over several

times to understand. I just don't feel like reading anymore due to my cognitive impairment.

- I get anxiety when struggling to read. My vision is blurry due to the medication I take and I am forgetful. I lose concentration very quickly. My memory and cognition is poor (**see attached cognition assessment**). I process everything really slowly. I need someone around to help me understand some signs. I feel anxious and struggling to read and this sometimes aggravate my pain level and triggers my crisis.
- I don't feel like reading at all; I need to be prompted to read. Complex signs and symbols are difficult for me.

### **Question 11 - Mixing with people**

**Q11a Yes**

**Q11b Yes**

#### **11c Extra information – Mixing with other people**

- I am isolated. My pain is too bad that all I want to do is lie down. I do not socialise as I feel different from other people. I have no energy to mix with people. My IBS is bad, I have bad flatulence and I am afraid I will do this in the mix of people and embarrass myself. I always feel dizzy with the medications I take for pain relief. I am always in atrial fibrillation so I just want to rest all the time.
- I need someone to encourage me or prompt me to socialise or go out and mix with other people. I only go to church on Sundays with my daughters when they are not with their friends. I get blackouts and fall without warning since my stroke.
- I cannot mix in a crowd. I am always nervous and ashamed that they will notice my disability. I feel people are staring at me or talking about me all the time. I feel I look awkward in the midst of people. There is stigma attached to the sickle cell disease in my cultural community so I feel people judge me as been snobbish without getting to know me so I do not socialise.
- I see the sickle cell disease psychologist at Guys Hospital to help me manage my social isolation and I attend the sickle cell support group where I receive counselling and help with reducing anxiety; the support group encourages on how to mix and be able to talk freely about sickle cell disease but this is difficult as most people do not understand it and this gets me angry with people and I hate myself for this.
- I get anxious or overwhelmed during or after doing this and this triggers my crisis and aggravates my pain. I also get tightening in my chest which triggers my angina when I see crowd or too many people. I feel nervous.
- I need someone to take me or to encourage me to go out or mix with people.

### **Question 12 - Making decisions about money**

Q12a Sometimes

Q12b Yes

**Q12c Extra information – Making decisions about money**

- I am never pain free and it's always difficult to make decisions about how much things cost or if there is a cheaper alternative or how much change I should get back. I just do not remember to count my change as I do not want people to know that I am struggling with the change. I even forget how much I give the cashier so I cannot argue the change. It's when I get home that my daughter will remind me of how much she gave me and how much change I should have. **(Pls see cognitive assessment report attached).**
- I do not carry money with me because I will lose it without knowing. My daughter makes money decision for me and buys things for me, even clothes as I do not have the energy to do it and also I cannot go shopping because I get confused. My daughter helps me decide on what to buy.
- I feel the same all day every day.
- I cannot manage spending; I overspend what I don't have because I have no sense of spending. I can't control money
- I get depressed afterwards as I am always short-changed. I feel embarrassed and anxious. I get tightening in my chest with pain. I need to be reminded to pay the household bills; I do this with direct debit but even then my daughter reminds me of the days the bills will be deducted so I can make money available in my account. My daughter monitors my account for me and my bills. I am in so much debt due to this problem.

**Question 13 – Going out**

Q13a Yes

Q13b Yes

Q13c Yes

**Q13d Extra information – going out**

- Due to the level of my pain, I find it difficult to plan or follow a route to places I am not familiar with. I am confused; I get blackout and falls since my stroke. I cannot get on the bus as the step is too high for me to climb in due to my AVN hips and pain in knees; also getting off the bus is difficult for me as it is too high. I am afraid of the underground because I get claustrophobic. I get palpitation and chest tightening which triggers my angina. I get confused on the underground.
- I need to be encouraged to undertake any journey at all.
- My daughters help me plan my route. I drive a Motability car at the moment and my daughter is an additional driver; often she take me to an unfamiliar places as I cannot do it alone for fear of getting lost or confused and I blackout.

- I plan 24 hours ahead of going anywhere unfamiliar to me. My daughter will have to encourage me and promise to go with me before I even agree to go.
- Unfamiliar places are worse, I get anxious and scared. I do not always go out alone; I always need someone to go with me and this distress me. The stress and the thought of going out can trigger my crisis
- I need someone to help me plan the route and I feel safer if someone goes around with me for support in case I feel dizzy or blackout or fall which happens all the time in unfamiliar places.

#### **Question 14 Moving around**

Q14a            Less than 20 metres

Q14b            Yes

Q14c            Yes

#### **14d Extra information – Moving around**

- I have avascular necrosis of both hips and meniscus tear in my knee. I am always in pain. Every step I take is painful but I can only manage about 10 to 12 metres walk before I start getting severe pain in my hips, back, legs and chest and need to take pain killers. I get angina pain on walking about 15 metres and I need to stop and rest and take my GTN spray which I carry around with me.
- At the moment I have a Motability vehicle which I drive and I have a blue badge as well which enables me park close to wherever I am going. If I do not have the Motability vehicle I will be housebound and depressed.
- It can take me up to 15 to 20 minutes to walk just 15 metres as I have to walk slowly so as not to aggravate my symptoms. exertion triggers my angina attack
- In the morning my pain is very bad and I cannot walk upright as I am in so much pain.
- I regularly fall and blackout. I find it difficult to climb stairs due to pain and coming down stair. I lose cognition and fall over due to lack of coordination. I get angina attack without warning so I carry my GTN spray around everywhere.
- I use walking stick to move around and I also have an electric scooter that I use to move around outside.
- I get breathless on exertion and get dizzy and totally blackout. This started since my stroke. I have limb length discrepancy since my stroke. This causes me to fall often. I need help moving around in case I fall or blackout. I need support to get back on my feet to stabilise. I cannot walk any distance without pain; every step I take is painful to me.