

PIP REVIEW/RENEWAL

PREPARING FOOD AND COOKING

Tell us if something has changed and approximately when.

Since 2016 I have had several painful episodes on my legs which the doctor said is Vaso-occlusive crisis, this occurred in 2018 till date. Which has added to the constant pains I get everyday because of my sickle cell. This has made it even more difficult to prepare or make food for myself.

Tell us how you manage this activity now, including the use of any aids that you need.

As a result of the constant pains in my leg and body I can't stand on my leg for a long period of time without the use of my wheelchair and walking stick. I get pains in my hands, fingers and elbows so I am unable to hold or use any equipment's to prepare my food without the help of my mother. I cannot bend my back or knee because of my Vaso-occlusive crisis to use the oven also; it's too painful and I get dizzy due to the number of medications I take to help to ease the pain that I go through everyday.

Tell us about any changes to the help you need or the help you get from another person.

I need my mum to cook my meals as I cannot make my meals by myself. She would also cut and chop onions 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. I have a kitchen stool to sit on and watch my mum as she prepares food as our kitchen is really small so my wheelchair can not fit inside it as I need constant supervision.

EATING AND DRINKING

Tell us if something has changed and approximately when

Additional stronger pain medications has been prescribed for me. The strong pain medication causes loss of appetite and constant constipation, because I have to take these medications every day to manage pain and discomfort I have all over my body. My mood has changed also, which means I need constant reminder and encouragement to eat. I am hardly hungry due to constipation, lack of appetite and always feeling full and bloated. The psychological challenge of trying to cope with constant pain that I am going through all over my body is emotionally draining and overwhelming to the extent that my focus is always about pain control, never about food.

Tell us how you manage this activity now, including the use of any aids that you need.

My bedroom is upstairs and the kitchen is downstairs, so my staircase can be challenging for me to tackle alone as my stairs add more pains to my leg and hands. I need help from my mum to help me down and up the stairs, this can take sometime which affects my mood and no longer have the appetite to eat. My migraines cause dizziness and blurry visions, this means that I can't see clearly and I'm unsteady on my feet. I lose my grip when holding on to things and cannot support myself without help. I need help to warm food and hot water to drink and it's so painful to eat. I eat in small portions. Because of the medications that I take, I find it hard to keep my food down because I get nauseous and throw up every time I eat. My mum needs to feed me and cut up my food in small portions so that I am able to keep something down.

Tell us about any changes to the help you need or the help you get from another person.

I can't use knife to cut meat or steak due to pain in hands and fingers and I have a poor grip. I cannot feed myself as a result of this and because of this my mum has to feed me food and drinks. She also tries to help me keep my food down because of the constant nausea caused by the strong medications I take to manage my pain all over my body. She also helps me by sitting me up to eat as it is painful to do it alone with every move I make, and she motivates me to eat as I have lost a lot of weight due to not being able to keep any food down.

MANAGING TREATMENTS

Tell us if something has changed and approximately when

Since 2017 I have been given higher dosage of medications and new additional medications to help with the pain I face every day. I find it a lot harder to concentrate because I am in a lot of pain and if I am unable to concentrate I find it very difficult in taking my medications. I also find it hard to read instructions and to follow instructions because of my constant dizzy spells from my agonising migraines. I need supervision when taking my medications everyday. I am not able to manage my health conditions reliably as health can descend without any warning signs and I will then need medical care from the hospital.

Tell us how you manage this activity now, including the use of any aids that you need.

I use a dosette box from Monday to Sunday to help me remember to take my medications. Most of the medications I use are difficult to swallow, so my mum would have to grind my medication to make it easier for me to take. Sickle cell affects my whole body, so it is important that I take my medications at the right time and the medications affect my moods and most times I forget to take my medications which my mum would have to set an alarm to remind herself to give me my medications at

the right time. I need hot water bottle to help manage my pains and most of the time I have swollen joints which the hot water bottle helps. I am unable to hold any heavy object, so my mum would prepare my hot water bottle.

Tell us about any changes to the help you need or the help you get from another person.

I have had counselling since 2016 which is provided after every check-up at my sickle cell clinic. NHS/Government declared me as a vulnerable patient and was advised to shield for over 3 months. I have had more anxieties, especially during lockdown because of COVID-19, scared to go into hospital and worrying that I could be affected by covid-19. My mum orders my prescriptions to be delivered and any other medical needs that I may need. My mum cannot leave my sight because half the time I am drowsy and nauseous from taking Morphine. My mum also helps me to massage in heat balm on my swollen body. With the medication I take it has side effects such as itching and there are some places that I am unable to reach alone so I need assistant from my mum.

WASHING/BATHING

Tell us if something has changed and approximately when

I have acute chest syndrome which means I have constant chest pains and which also means that I get breathless from any small movements. With the pains on my legs I can not assist myself to have a wash without assistance. I need to be assisted to go in and out of the bath tub, the pains on legs, hands and chest makes it a lot difficult with every movement. Because of my migraines and medications I get dizzy and black out when bathing and getting in and out of the bath. This means that I need to hold on to someone for assistance not to fall. I also need prompting to bathe due to my pain and being anxious thinking about it.

Tell us how you manage this activity now, including the use of any aids that you need.

I have to grab hold of my railings with my painful fingers and hands to assist with getting in the bath, as I can't grab on as firmly, my mum needs to assist me in and out of the bath. If no one is home I wouldn't be able to wash myself because I'm not able to get into the bath to begin with. I need to sit on a stool when I am in the bath. The bath can get slippery and with my painful legs I can't stand for that long period of time to have a wash. It can take 30 to 40 mins to have my bath. Because of the pains I am in I need to do everything slowly, standing, sitting and holding on.

Tell us about any changes to the help you need or the help you get from another person.

I get anxious before starting this activity as I am afraid to shower as it is difficult to move my hands around due to pain in my fingers, hands, elbows and shoulders. I cannot reach my back, buttocks and backside without assistance. My mum needs to take her time when washing my legs as they are very painful. I always have aggravation on my back and leg pain, and hands after this activity. I also have shortness of breath because of my chest pains and every time I have my shower I need constant supervision.

MANAGING TOILET NEEDS OR INCONTINENCE

Tell us if something has changed and approximately when

My toilet needs has worsened since having vaso-occlusive crisis on my leg. I have to use the door handle to help me seat down on the toilet. I cannot sit down on a standard toilet seat; it's too low for me because of the pains on my back and legs. Also I cannot get up from a low toilet seat without assistance because of my painful legs, knees and back. Because of the medications that I take for my pains I get constipated and find it very difficult to open my bowels, the straining pain to open my bowels causes more pains to my whole body.

Tell us how you manage this activity now, including the use of any aids that you need.

My mum has to support me when using the toilet as I cannot use it alone without feeling dizzy from the medications and making the pains on my leg worse. I also need to use my crutches when approaching the toilet to support my weight as my mum can not carry me alone. I also need to hold on to my heater railings and sink to help me sit on the toilet which still causes more pain to my legs, knees, fingers and hands.

Tell us about any changes to the help you need or the help you get from another person.

I get alternating diarrhoea and constipation so it becomes very painful when passing stools. With the medications I use I get nauseous and I can vomit at the same time as passing hard stools. It takes me 30 to 40mins to get out of bed and into the toilet, so I wet the bed and can't control my bowel movements most times and I have to wear Tena pants for incontinence. I am also unable to wipe myself after using the toilet because of the pains on my back, hands, and fingers, so my mum needs to assist me when wiping myself. After sitting for a long time my chest pains gets worse and I need help with getting up straight again feeling, breathless and fatigue.

DRESSING AND UNDESSING

Tell us if something has changed and approximately when

My undressing and dressing has worsened since 2017, my pains on hands and legs has made it a lot difficult to dress myself. I cannot stand to dress myself because of my painful crisis on my leg. I have to sit-down due to pain in my lower back and knees. I need assistance to put on my socks, tights, trousers and shoes as I cannot bend low due to pain on my back and legs. I cannot do my bra at the back by myself due to pains on my back, hands and shoulders. Also I cannot zip my dresses at the back due to painful hands and arms. I get dizzy spells bending down because of the medications I am currently on to help manage my pains. I cannot cream my upper and lower body or back due to pain and restricted limb movement.

Tell us how you manage this activity now, including the use of any aids that you need.

My mum helps and supports me when sitting up on the bed to change my clothes. She raises my arms as I cannot do so by myself. Mum sits me down on a chair because my back needs to be supported when dressing me and undressing me. She assists me to pull up my underwear and trousers as my back pains limits me in doing so. I also wear baggy clothes so that my movement around it is easier.

Tell us about any changes to the help you need or the help you get from another person.

Most of the time I am in pain so I tend to fall asleep whenever my mum dresses me and undresses me. Every time I am undressing and dressing I get really exhausted from the movements and pains all over my body. I cannot wear shoes with laces or buckles as I cannot bend down to do them. I do not wear bras most days because they hurt my chest with the painful crisis I have frequently. It can take me up to 30 to 45 minutes to get dressed as I struggle a lot without help from my mum.

SPEAKING TO PEOPLE, HEARING AND UNDERSTANDING WHAT THEY SAY AND BEING UNDERSTOOD

Tell us if something has changed and approximately when

My migraines and sickle cell pains has gotten worse over the last 2 years and it has affected my communication abilities. I get brain fog due to the level of my pain and this has caused some difficulties when hearing and understanding what others are saying. Due to the number of medication I take to help manage my constant pains, I get confused when communicating with people because of how drowsy I am and people cannot hear me because my speech falters.

Tell us how you manage this activity now, including the use of any aids that you need.

I lose track of my sentences and communication and cannot understand what people say to me, so most of the time my mum would have to explain what I am trying to say, and she would also explain to me what others are trying to say to me. My mum would ask me to blink once for No and blink twice for yes when she's communicating to me.

Tell us about any changes to the help you need or the help you get from another person.

I have pains in ears which is caused by my sickle cell and I find it hard to hear others. Because of this reason I have a low self-esteem and have anxieties every time I have to communicate with others. I get palpitation and chest pain when I cannot express myself clearly and embarrassed when people cannot understand me. My mum is always by my side whenever I feel this way and tries to keep me calm by explaining to me what I find difficult to understand.

READING AND UNDERSTANDING SIGNS, SYMBOLS AND WRITTEN WORDS

Tell us if something has changed and approximately when

With my sickle cell pains and migraines it is very difficult for me to focus. I have learning difficulties that affects all areas of cognition and learning. I am unable to read or understand full sentences because of my illness and strong medications that I take. I am never pain free and also due to my constant migraines I have memory impairment where I get confused trying to understand what I am reading. I find it difficult reading complex written information and I cannot read or understand signs, symbols or words; it's too difficult for me because of this I need someone to help me understand.

Tell us how you manage this activity now, including the use of any aids that you need.

I use reading glasses most times to help me see what I am reading as my eyes tend to get blurry with the strong medications that I use. With the migraines I get because of sickle cell it affects my eyes, because I get constant sharp pains at the back of my eyes. My mum would need to help me read and help me to understand each signs and symbols. Without her help I wouldn't be able to read and understand any words, signs or symbols.

Tell us about any changes to the help you need or the help you get from another person.

I struggle to perform everyday activities because of my sickle cell pains and migraines. I don't feel like reading at all; I need to be prompted to read by my mum. I find it difficult to understand complex signs and symbols. I feel anxious and struggle to read and this sometimes aggravates my pain level and triggers my crisis. My mum helps me to read each words and tries to control my anxiety level whenever I get upset about not being able understand what I am reading.

MIXING WITH OTHER PEOPLE

Tell us if something has changed and approximately when

With COVID-19 that happened this year, it has been extremely difficult mixing with people. Having sickle cell makes me a vulnerable patient and at high risks of getting COVID-19. Because of this I have hardly been outside. Before COVID I didn't go out at all because I am constantly in pain and drowsy from all the medications. I find it very difficult engaging with people as they can not understand me when communicating with them.

Tell us how you manage this activity now, including the use of any aids that you need.

Because of sickness, I have lost a lot of contact with my friends, my mum is the only person that I spend time with. Whenever I engage with others I get extremely distressed and my mum gets worried that it could be harmful to myself or to others. My mum would have to be around me constantly to keep an eye on me whenever I am trying to engage with someone else. I cannot mix in a crowd so I isolate myself as I am always nervous and ashamed that they will notice my disability.

Tell us about any changes to the help you need or the help you get from another person.

I am always tired and in need of rest that I always feel dizzy with the medications I take for pain relief. With my chest pains, it takes a lot out of me to put together a sentence as I get breathless with each words. There is stigma attached to the sickle cell disease in my cultural community so I feel as though I am being judged whenever I am around people from the same cultural background. I depend on my mum everyday whenever I feel anxiety when engaging with people as she knows me best.

MAKING DECISIONS ABOUT SPENDING AND MANAGING YOUR MONEY

Tell us if something has changed and approximately when

After Covid-19 my mum made the decision not to bring in or deal with cash or coins as this can also pass the disease to vulnerable people with weak immune systems such as my case. I do not handle my finances as I cannot understand what I am doing and I get anxious every time I have to deal with money. I am never pain free and it's always difficult to make decisions about how much things cost and if there is a cheaper alternative.

Tell us how you manage this activity now, including the use of any aids that you need.

Every transactions is done by direct debit and handled by mum because of the pains on my fingers and hands I am constantly making a mistake every time I try to send money from my account. My mum is then left to sort through everything as I can not make a budgeting decisions without feeling anxious about not being able to understand the symbols and words. Also I cannot go shopping because I get confused and have anxiety being around that many people, my mum helps me to decide on what to buy but most times my mum does online delivery for me.

Tell us about any changes to the help you need or the help you get from another person.

With my disability I cannot manage my spending and I always overspend what I don't have because I have no sense of spending. I get tightening in my chest with pain and breathless every time this happens. I need to be reminded to pay my bills; I do this with direct debit but even then my mum reminds me of the days the bills will be deducted. My mum as access to my accounts and monitors my account for me including my bills.

PLANNING AND FOLLOWING A ROUTE TO ANOTHER PLACE.

Tell us if something has changed and approximately when

Since 2016, having constant migraines and chest pains affects me terribly as I am always dizzy and nauseous from the medications. I can not read a map or follow a route without getting lost. I need to be encouraged to undertake any journey at all. I have to plan my journey at least a week in advance because of my disability. Anywhere I go to needs to have ramps for my wheel chair, handles to hold on to, and disabled toilets and non-crowded areas.

Tell us how you manage this activity now, including the use of any aids that you need.

Again I can not plan my routes without assistance from my mum. My mum wouldn't feel confident with me following a route without getting lost without her being there. I need someone to be there with me to direct me and read signs on the roads to get to my destinations. I get severely depressed whenever I go out and I do not make eye contact with people whenever I am out.

Tell us about any changes to the help you need or the help you get from another person.

I would have to call my doctors to plan my journey to attend my appointments. Because of depression I have to speak to the counselling team in the hospital to help me cope with my suicidal thoughts. Unfamiliar places makes things worse for me as 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.

MOVING AROUND

Tell us how you manage this activity now, including the use of any aids that you need.

I am unable to hold my body weight because of my bad leg and painful fingers and hands. I am always in pain because of sickle cell and 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 back, legs and chest and need to take my pain killers. My wheelchair helps me to move around without straining myself. Whenever I need to stand I would then need to use my crutches to support me and my mum would give me a hand also.

Tell us about any changes to the help you need or the help you get from another person.

I can't go more than 10 meters without feeling short of breath from my chest pains. My medications makes me dizzy and can fall if I do not have any support next to me. At the moment I have a Mobility vehicle and a disabled badge which enables me park close to wherever I am going. If I do not have the Motability vehicle I will be housebound and depress. I find it very difficult to climb and go down the stairs due to pain on my chest, legs. I lose cognition and fall over due to lack of coordination. I cannot walk any distance without pain; every step I take is painful to me.

IS THERE ANYTHING ELSE YOU THINK WE SHOULD KNOW ABOUT YOUR HEALTH CONDITION OR DISABILITY?

Because of Covid-19 I have been scared to go to the hospital when I am in extreme pain. My depression has gotten worse also because I haven't been able to socialise with anyone. My pain on my legs and chest makes it a lot harder for me to make any sudden movements without being breathless and dizzy. I have been bed bound this past 6 months as I am too anxious about covid-19 and scared that I will catch this virus as my immune system is extremely low. I am currently not working, so my mum is my only source of income. I have only had to go into hospital when my pain is unbearable and it is only to the day clinic because I am too scared of contracting covid-19. My mum has not left my side and she is my only support that I have. Getting all the support that I can get from PIP would ease things for me and my mum. My mobility vehicle is the only way that I am able to get to and from my hospital clinics and appointments, this has relived a lot of the pressure for my mum.