

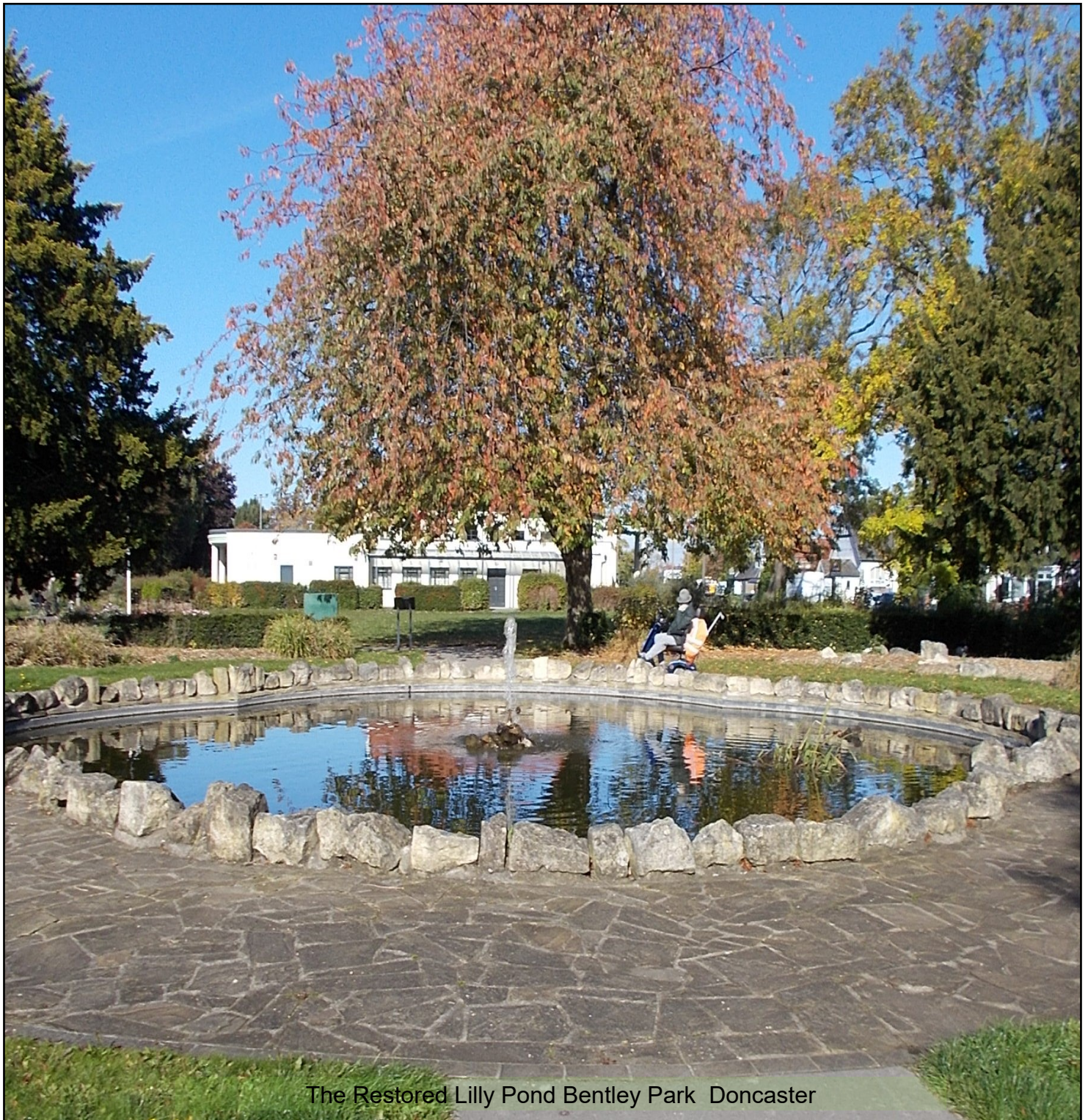
# Pathways

Price £ 5.00 (Free to members)

*The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers*

## **Welcome to Pathways No 73. Autumn 2022 Edition.**

### **More About Help on the Energy Squeeze and ME/CFS**



The Restored Lilly Pond Bentley Park Doncaster



## You write in

**Bill writes:** *I have seen the news, read the papers, watched the Internet. I still do not understand what is happening and why things are going up? Could you please explain?*

Good question and there is no one simple answer. Here is my understanding.

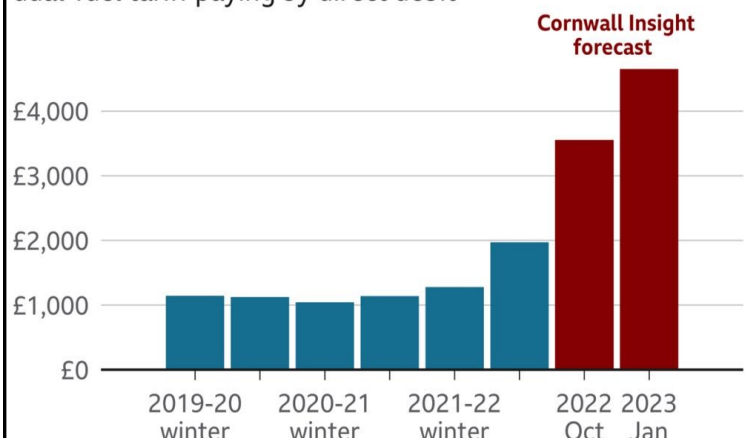
Firstly we had Covid pandemic. This caused havoc with world trade, caused shortages and closed down many businesses. This started in early 2020. Earlier this year we started to emerge from the pandemic. However, it was forecast that there would be price inflation by the Bank of England and other financial institutions following the waning of the pandemic. However things are not that simple. Covid is still around and is causing problems and has only added to the long standing lack of funding for the NHS. So, part of the problem is due to Covid, and its legacy effects which are likely to last for many years to come.

Secondly, earlier on this year Mr Putin the Russian leader decided to try to claim back the Ukraine and annex it to Russia. What is quite clear is that the Russian Army was poorly equipped and trained, and also had poor leadership. Ukraine went to war with Russia to try to get back the land in the west annexed by Russia. NATO, the west and ourselves, have given Ukraine arms to fight the Russians and to some extent the Ukrainians are winning. However, Russia is 'bombing' Ukraine with drones and guided missiles from over the horizon. The war continues. However, it is costing Russia dearly in financial and social terms. Russia being the worlds biggest country has its own coal, natural gas and oil reserves which it has been selling at low cost to Europe and other countries including the west and NATO. As a sanction the West has decided to stop buying energy products from Russia in the hope that it will squeeze Russia's finances. Because energy products are bought on an open world market, the price of gas and oil has risen worldwide dramatically.

For us in the UK, the price of electricity has also gone up because most electricity is generated from gas. The biggest component cost is the wholesale cost of gas, which has to be passed onto the customer. A complication is that oil and gas are bought in dollars. So any change in the exchange rate and affect the price of fuel.

### Energy price cap forecast to rise to £4,650

Annual bill for a typical household on a price capped dual-fuel tariff paying by direct debit



### How your fuel bill is broken down

Typical customer on a price capped dual-fuel tariff paying by direct debit from 1 October 2022

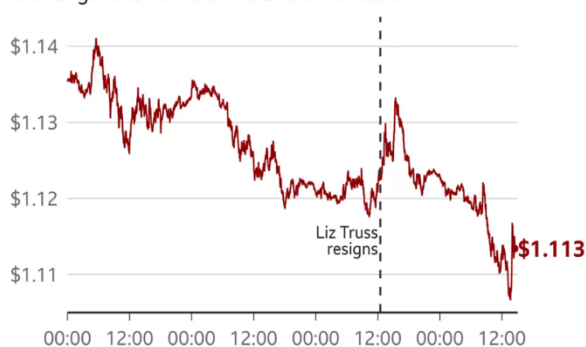
Total annual cost: £3,549



\*Wholesale costs include profits to extractors

### Pound vs US dollar

Exchange rate between 18 and 21 October



Source: Bloomberg. Last update: 21 October 2022, 14:30 BST

BBC

Most recently ex Prime Ministers Liz Truss's budget plans caused a fall in the pound/dollar exchange rates, which has resulted in 2-3% increase in overall energy prices for us here. The rise in interest rates and mortgages is a direct result of this due to a series of complex financial reactions,

There is of course the cushioning support for energy bills from Government - but ultimately the extra costs have to be paid for in some way of other. For the future there is no doubt that costs will rise, and at the time of writing the Governments Energy Caps Subsidy is due to stop at the end of March 2023. We all have to wait and see what happens.

**Karen Writes:** *A have read in the Sunday newspaper that artificial sweeteners may be linked to higher Cardiovascular event risks e.g., heart attacks and strokes. Is this true, and what can I do about it?*

Saccharin based sweeteners have been around for many years without adverse effects. It is the newer ones that are a problem. Recent studies published in the British Medical Journal have shown the risk is increased by about 9% in a French study of 103,388 French adults. About 38% reported consumption of artificial sweeteners. The sweeteners assessed were mainly aspartame (58% of sweetener intake), acesulfame potassium (29%), and sucralose (10%), with the other 3% made up of various other sweeteners including cyclamates (banned in the UK) and saccharin. Just over half of the artificial sweetener intake in the study came from drinks, with the rest coming from tabletop sweeteners and foods.

Health concerns about the consumption of artificial sweeteners have been around for many years. The simple answer is to avoid products that contain them. However, you also have to consider the other cardiovascular risk factors like smoking, being overweight, high blood pressure, cholesterol levels and other chronic disease problems.

**Jennine writes:** *Throughout that Covid lockdown I have joined an organisation that deals with people who are trying to help people mitigate alcohol and drug issues. I have enjoyed the social integration and I have found them helpful in a way. They have asked me to help out as a volunteer, but I have concerns that they do not understand I have ME/CFS and what it is all about. I think I am being treated in a similar way to those with alcohol and drug misuse issues.*

*I am there for my mental health issues. I try to inform them without banging a drum. It is hard to explain to them, to get them to understand that I need rests in between. And even an hour course/volunteering means preparation beforehand for me. Effort, energy, thinking. I feel they maybe wanting to meet quotas by those who run it.*

*Would it be possible for someone to write a letter explaining the issues to non-believers?*

Firstly, we have sent you a pack entitled "This is ME/CFS", and a factsheet from Benefits & Work Jan 2007, entitled, "Reasonable Adjustments"

The 'This is ME/CFS' literature is intended to give brief information about ME/CFS to people who do not understand the ME/CFS issues. It was pioneered from a joint project by Action for ME and the North Bristol ME/CFS clinic. It contains a form for you to complete which you can give to someone else like a volunteer supervisor. This makes perfectly clear the limitations of ME/CFS. It also helps with their requirement for health and safety assessments. It is really only you that knows how you feel about ME/CFS and what your limitations are. If you have any difficulty, come back to us, and we will intervene if necessary. The ME Association have produced something similar, part of which is reproduced in later pages of this issue.

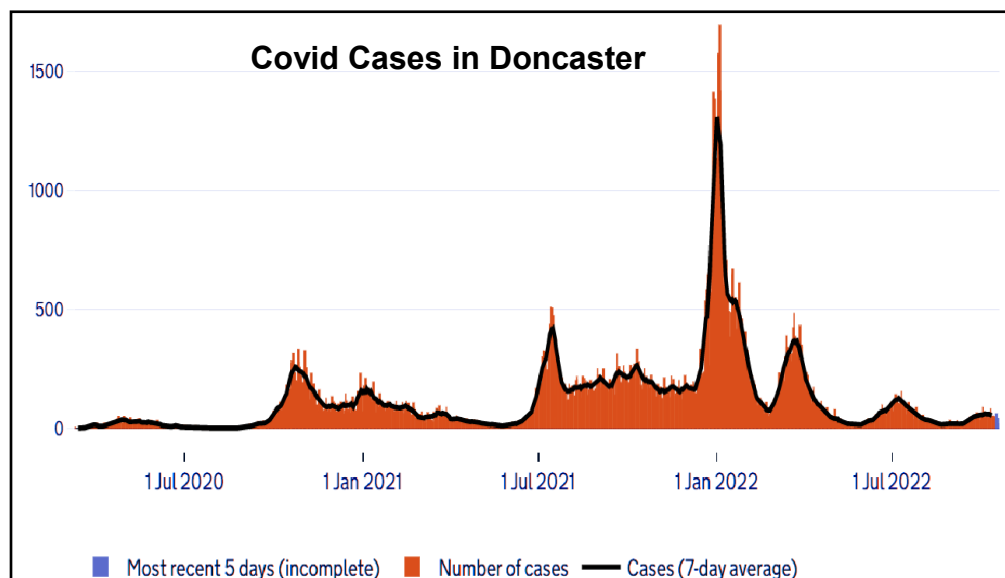
The "Reasonable Adjustments" literature is intended to help an employer or volunteer supervisor understand what they need to do to allow you to work while protecting your health. Issues I've seen are things like accessible toilets, and people being expected to work 200-300 yards from a toilet. People with ME/CFS need access to a toilets, maybe every few hours, far more than a normal person. Photophobia is a common problem. Special lighting and avoidance of bright lights may be needed. That could easily be fixed with a light dimmer or special lighting. Some people may need special seating. There are loads of designs to help people with disabilities, but they are expensive and may be a put off to volunteering for an organisation. There may be a need for a quiet area because of hyperacusis. Then there is that thorny issue about rebounds. You might be able to do something quite well on a good day, but maybe not the following days. This could be a problem if you have to supervise or be a key holder. My advice would be to avoid anything like this because it would not be in your interest to pass continue it. Then there are out of pocket expenses -e.g., bus fares special clothing. You should not be expected to wash work clothing as it would be the responsibility of the organisation.

Finally, do not forget that you still have to Pace to control your ME/CFS. You have to be in a position to say NO without offending.

## Covid Matters Update.

Covid 19 has not gone away, it is still very much around and likely to remain so for years to come.

The graph on the right is taken from the Government website as of the 21st of October. The take home message is that Covid is still very much around, and still capable of infecting, causing long covid and even killing people. Around the Doncaster area the infection rate between 100 - 200 cases per 100,000 people.



As well as In Doncaster, nationally, people are continuing to experience a rise in Covid-19 cases, with the number of inpatients at Doncaster and Bassetlaw Teaching Hospitals who have tested positive for coronavirus rising above 100. With this in mind, it is important that we continue to protect ourselves, others and our NHS and Social Care services this Winter.

Vaccination is the best way to protect yourself from serious illness ahead of Winter. If you are eligible for a flu jab or the Covid-19 Autumn booster, please get them as soon as you can. Check the NHS South Yorkshire website for more details.

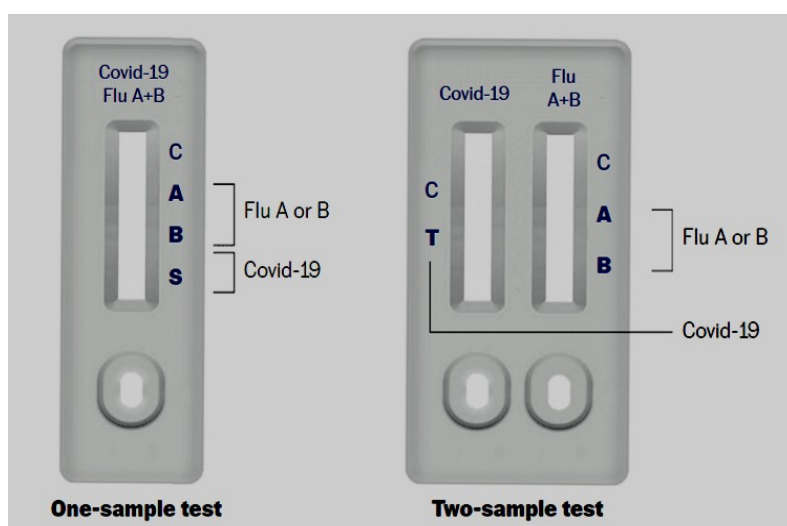
Locally, to reduce the risk of spreading flu and covid-19, remember to catch it, bin it, kill it - use tissues to sneeze and cough into, bin them immediately and continue to wash your hands regularly and thoroughly. If you are feeling unwell or if you have symptoms of Covid-19, you should avoid close contact with others until you feel better.

The rise in cases of coronavirus puts additional pressure on health services. You can help by only attending A&E if you need urgent or emergency care. If you are unsure, please use NHS 111. When visiting any healthcare setting, please also remember to take and wear a face covering.

What is happening in the Southern Hemisphere e.g., Australia is that they are coming out of their winter into their Summer. Now the lockdown and anti-infective precautions have been relaxed. It looks like flu is remerging with vengeance. In fact, there is great concern among the experts that a virulent strain of flu may emerge and cause havoc especially because the Covid precautions have limited exposure to flu. The experts in the UK are very worried about this situation. So, at present both Covid and 'Flu Vaccinations are being promoted by the NHS. Please see the following pages regarding advice about seasonal vaccinations.

## Dual tests for Covid and 'Flu

*Gill, one of our members has brought to my attention a variation of the lateral flows tests which tests both Covid and Flu (types A and B). These test are used abroad where there is no formal Health Service. I am unclear about the context of these tests and how they would be used. I can see that they could be useful in hospital or nursing care for screening visitors of vulnerable patients who cannot be vaccinated. However, within the NHS and the UK I cannot see these in routine use.*





## ***Covid booster and flu jab update (October 2022)***

Back in February, the Joint Committee on Vaccination and Immunisation (JCVI) said: *"Despite the known uncertainties in the year ahead, Winter will remain the season when the threat from Covid 19 is greatest both for individuals and for health communities. It is JCVI's interim view that an Autumn 2022 programme of vaccinations will be indicated for persons who are at higher risk of severe Covid 19; such as those of older age and in a clinical risk group."* On 15th July, the Government shared JCVI's final recommendations for this Autumn's programme.

Under the advice, those eligible for a further dose will be:

- all adults aged 50 years and over
- those aged 5 to 49 years in a clinical risk group, including pregnant women\*
- those aged 5 to 49 years who are household contacts of people with immunosuppression
- those aged 16 to 49 years who are carers
- residents in a care home for older adults and staff working in care homes for older adults
- frontline health and social care workers
- Clinical risk groups are set by the JCVI in its Green Book, Chapter 14a.

While this doesn't specifically list ME/CFS under its "chronic neurological disease" category, it does make the following clear. *"The examples above are not exhaustive, and, within these groups, the prescriber should apply clinical judgment to take into account the risk of Covid 19 exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from Covid 19 itself."*

In addition, the Department of Health and Social Care will be widening the offer of the free flu vaccine to more eligible groups. These additional groups will only be eligible once the most vulnerable, including previously announced pre-school and primary school children, those aged 65 years and over and those in clinical risk groups, have been offered the jab. The additional groups set to be offered the free flu vaccine in England will be all adults aged 50 to 64 years followed by secondary school children in years 7, 8 and 9, who will be offered the vaccine in order of school year, starting with the youngest first.

The NHS will announce in due course when and how eligible groups will be able to book an appointment for their Covid 19 Autumn booster, and when people aged 50 to 64 years old who are not in a clinical risk group will be able to get their free flu jab. People in these groups are asked not to come forward until further information is announced.

### **What about people who have had problems with previous vaccinations?**

The UK Health Security Agency's leaflet Covid-19: *Your guide to booster vaccination*, says: *"If you had serious side effects after any previous dose you may be advised to avoid or delay further vaccination. You should discuss this with your doctor or specialist."*

If possible, everyone who has tolerated Covid and Flu vaccinations last season should have their booster. Our advice to people with ME/CFS is to have the two jabs separately, and least 14 days apart as two jabs given at the same time may cause a relapse or rebound.

**Covid Vaccinations:** There are no AZ (adenovirus shell) jabs as these caused too many unacceptable side effects, and should be avoided at all costs. This year's boosters contain two strains of Covid. They are either Pfizer or Moderna in origin. One is the original strain, and one is the Omicron BA1 strain. People who have had this year's jab report that the side effects are as intense and last as long as their very first Covid jab. Most people didn't react to the follow up Covid jabs.

**Flu vaccinations:** This year's vaccination contains 4 flu strains. If possible we recommend that you have the egg free vaccines as they are much cleaner, and have a cleaner reduced side effect profile. The people who have had the jabs report soreness at the point of injection, and malaise for a few days, but nowhere near as intense as the Covid jabs.

## Welfare Rights News

*With thanks to Benefits and Work*

### Benefits Threat

Working age benefits are threatened with a real terms cut in value next April and now is the time to act. Liz Truss is said to be keen to uprate benefits only by 5%, in line with wages, instead of the 10% inflation-linked rise that claimants should be getting. An increasing number of high profile Tories are coming out to publicly back a 10% rise and it is looking harder and harder for Truss to avoid another U-turn. However, the government are in a desperate mess trying to find ways to cover the cost of their unfunded tax cuts.

The Institute for Fiscal Studies has warned that Truss needs to find £60bn of savings. A cut in uprating of working age benefits (disability benefits are seen as less of a target) would save a tempting £13bn. Faced with a choice between reducing benefits, abandoning her tax cuts, or spooking the money markets Mrs. Truss may still decide to go after claimants. A final decision has yet to be made and the result will not be announced until 31st October. So, we are urging readers to contact your MP, especially if they are a Conservative, and encourage them to support the 10% increase. Just for once, they might be ready to speak up for claimants, even if it is only to try to save their own seats in the face of historically awful poll results.

### Missing 150 Payment Report Form

The DWP claim they have processed over six million £150 cost of living payments for disabled claimants, but some of our readers have still not received theirs. The department have now published an online a Report a missing Cost of Living Payment form which should be used if you are still waiting. They say they will get back to you within two weeks of receiving the form. We will let you know if we hear back from readers who have completed it.

### Second Cost of Living Payment Dates Confirmed

The £324 Cost of Living Payment, which follows on from a £326 payment made in July, will be paid out from 8th to 23rd November. The second payment will automatically be paid into the bank accounts of those who receive a qualifying benefit. means that, in theory, will not need to do anything to receive the money. Though, as the existence of the missing payment form above shows, things do not always run smoothly.

### Pay Pip Now Campaign Launched by Macmillan

MacMillan has now launched its campaign on PIP waiting times and they are asking Benefits and Work readers to help out by signing their petition and highlighting it on social media. MacMillan say that:

*The current average waiting time for PIP for people making a new claim in England and Wales is 18 weeks. It is unacceptable that people living with cancer are facing a such a long wait to receive the financial support they need and are entitled to.*

We are calling for the UK Government to reduce PIP waiting times to 12 weeks, so that people with cancer get this support when they need it the most. You can sign the petition and find out how to promote the campaign on social media.

## What has been announced?

### Cost of living payments



8m lowest income households

**£650**

Universal credit



8m pensioner households

**£300**

Receiving State Pension



6m receiving non means-tested disability benefits

**£150**

DLA, AA and PIP



Energy grant for all households

**£400**

Credited by energy provider

**Benefits and Work**  
Guides you can trust   
**SUPPORTING CLAIMANTS SINCE 2002**

*Leger ME members have access to Benefits and work guides as part of the membership benefits.*

*For further details please contact the office.*



## ***Personal Independence Payment (PIP) points system***

Almost everyone in Leger ME would qualify for some level of PIP if they applied for it. However, there are many hurdles and pitfalls on the way to get it. The claims form and claims process are far from ideal. We know as a group that many refusals for PIP as well as other DWP benefits are due to forms or information not being presented in the correct manner. This is why as a group we offer a Welfare Rights Mentoring Service. Here are the Activities and descriptors in brief: The most common sources of points for typical people with ME/CFS is highlighted in blue.

### **Daily living activities**

#### **1. Preparing food.**

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

#### **2. Taking nutrition.**

- a. Can take nutrition unaided. **0 points.**
- b. Needs –
  - (i) to use an aid or appliance to be able to take nutrition; or
  - (ii) supervision to be able to take nutrition; or
  - (iii) assistance to be able to cut up food. **2 points.**
- c. Needs a therapeutic source to be able to take nutrition. **2 points.**
- d. Needs prompting to be able to take nutrition. **4 points.**
- e. Needs assistance to be able to manage a therapeutic source to take nutrition. **6 points.**
- f. Cannot convey food and drink to their mouth and needs another person to do so. **10 points.**

#### **3. Managing therapy or monitoring a health condition.**

- a. Either –
  - (i) does not receive medication or therapy or need to monitor a health condition; or
  - (ii) can manage medication or therapy or monitor a health condition unaided. **0 points.**
- b. Needs any one or more of the following –
  - (i) to use an aid or appliance to be able to manage medication.
  - (ii) supervision, prompting or assistance to be able to manage medication.
  - (iii) supervision, prompting or assistance to be able to monitor a health condition. **1 point.**
- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **2 points.**
- 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 points.**
- 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 points.**
- f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **8 points.**

#### **4. Washing and bathing.**

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

**5. Managing toilet needs or incontinence.**

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

**6. Dressing and undressing.**

- a. Can dress and undress unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to dress or undress. **2 points.**
- c. Needs either -
  - (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
  - (ii) prompting or assistance to be able to select appropriate clothing. **2 points.**
- d. Needs assistance to be able to dress or undress their lower body. **2 points.**
- e. Needs assistance to be able to dress or undress their upper body. **4 points.**
- f. Cannot dress or undress at all. **8 points.**

**7. Communicating verbally.**

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

**8. Reading and understanding signs, symbols, and words.**

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **0 points.**
- 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 points.**
- c. Needs prompting to be able to read or understand complex written information. **2 points.**
- d. Needs prompting to be able to read or understand basic written information. **4 points.**
- e. Cannot read or understand signs, symbols, or words at all. **8 points.**

**9. Engaging with other people face-to-face**

- a. Can engage with other people unaided. **0 points.**
- b. Needs prompting to be able to engage with other people. **2 points.**
- c. Needs social support to be able to engage with other people. **4 points.**
- d. Cannot engage with other people due to such engagement causing either –
  - (i) overwhelming psychological distress to the claimant; or
  - (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **8 points.**

**10. Making budgeting decisions.**

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

*In sections 7 to 10, our members hardly ever score any points. Despite the well-known issues around brain fog, word mixing displayed by many members. I have never seen any points awarded on this section for ME/CFS. I only see points in these sections if there are major mental health issues which need a psychiatrist's intervention. Many members I deal with need to use a hearing aid. If one is prescribed, this would give someone two points for communicating verbally under section 7b. Very often I will signpost people to have a hearing test during a case review session.*



## Mobility activities

### 1. Planning and following journeys.

a. Can plan and follow the route of a journey unaided. **0 points.**

b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. **4 points.**

c. Cannot plan the route of a journey. **8 points.**

d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. **10 points.**

e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. **10 points.**

f. Cannot follow the route of a familiar journey without another person, an assistance dog, or an orientation aid. **12 points.**

### 2. Moving around.

a. Can stand and then move more than 200 metres, either aided or unaided. **0 points.**

b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. **4 points.**

c. Can stand and then move unaided more than 20 metres but no more than 50 metres. **8 points.**

d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. **10 points.**

e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. **12 points.**

f. Cannot, either aided or unaided, –

(i) stand; or

(ii) move more than 1 metre. **12 points.**

If you read the tariff, you will notice that nothing directly relates to fatigue, pain or ME/CFS. For example, you may walk a distance on one occasion, but not on the following days. 'Reliably' - the most important PIP word. It is vital that, before you complete your form, you understand that just because you can carry out an activity, which does not mean you are prevented from scoring points for being unable to do it. Guidance issued by the DWP states that you need to be able to complete an activity 'reliably' in order for it to apply. According to the guidance, 'reliably' means whether you can do so:

Safely – in a fashion that is unlikely to cause harm to themselves or to another person. (

To a necessary and acceptable standard – given the nature of the activity.

Repeatedly – as often as is reasonably required.

In a reasonable time period no more than twice as long as a person without a physical or mental health condition would take to conduct the activity.

The DWP guidance also states that 'pain, fatigue, breathlessness, nausea and motivation' will all be 'key factors' in deciding whether an activity can be done reliably.

### Additional Information: Variable and fluctuating conditions like ME/CFS

Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore, the descriptor choice should be based on consideration of a 12-month period.

Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period. The following rules apply:

*If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e., the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.*

*If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.*

## Gardening Corner by Carolyn

After a very strange Summer weatherwise followed by hose ban rules, I decided enough was enough and began to put the garden to bed ready for Winter rather earlier than usual. I lasted about three weeks, thinking how great it was not having to worry about all the outdoor plants anymore when the thought crossed my mind 'lets make the sitting room all nice and cheery for Winter time', and that was it I was off researching indoor plants. I don't suppose anyone will be surprised to know the house is now filling up!!

First, I needed to look at what we already have, in particular a little Wild Moth Orchid with pretty white flowers that isn't doing so well now so in came its big sister, ah, but now I have learned a lot more about the needs of orchids so, in came also, a lovely glass lantern container to ensure that the roots of the plant get plenty of light and, yes, I have also bought another glass container for the original one in the hopes it will do better.



*Wild Moth Orchid*



*Guzmania 'Francesca' bromeliad*

The next plant to arrive was Guzmania 'Francesca' bromeliad. Francesca, looks as exotic as her name, but it is proving to be very easy to care for and is already sprouting two more flower shoots. Liking bright filtered light the corner between two windows is where Francesca seems to be very happy.

I love to have some plants to grow purely for their foliage and decided to try Tradescantia albiflora



*Tradescantia albiflora 'Nanouk'*

'Nanouk' known as Moses in the cradle to many. It is fast growing and with its bright green and purple/pink foliage it is becoming a delightful indoor plant to enjoy. It loves bright but indirect light.



*Philodendron scandens 'Brasil'*

A foliage plant that is more unusual is Philodendron scandens 'Brasil', also known as 'sweetheart plant' and it is proving to be a real 'sweetheart' to own with its lustrous heart shaped leaves. It can be grown as a climber up a moss pole or let it cascade down the pot as I am hoping mine will do where it will eventually form a soft green curtain down the window sill.

In total I now have fifteen indoor plants including the four new ones this Autumn. It is taking time and there have been some failures but, slowly and steadily I am learning all about houseplants and how to care for them and finding it to be a very therapeutic hobby.



## ***Guiding Future Research: The ME/CFS Priority Setting Partnership.***

*With Thanks to Action for ME and Interaction Autumn 2022.*

The ME/CFS Priority Setting Partnership (PSP) has completed a participatory process to identify the Top 10+ ME research priorities to influence future research funding. The questions, outlined in a new report called Defining future ME/CFS research and presented on the opposite page, give a clear direction for research priorities to drive forward better treatments for people living with ME/CFS. It is hoped these will change the ME/CFS research landscape in the UK and beyond. The partnership was led by people with ME/CFS, their Carers and clinicians, facilitated by non-profit making initiative, the James Lind Alliance (JLA), and coordinated by Action for ME/CFS. Sonya Chowdhury, Chief Executive, Action for M.E said. "We now have our Top 10+ priorities, but this is just a start. It is essential that we work together with researchers, institutions, funders, and policy/decision-makers to form programmes of research to take the priorities forward

### **How the process worked:**

To complete this exercise, the JLA's well-established processes were followed, but adapted for the needs of people with ME/CFS. A steering group was convened from the ME/CFS organisations that initiated the Partnership, plus people with ME/CFS, Carers and health care professionals recruited via open advertisement. The steering group's job was to define the scope of the project, ensure equitable access, oversee all stages of the process, and draft the final report. Action for ME/CFS was funded to provide administrative support and coordination throughout, but every decision was taken by the steering group as a whole. The first stage was to gather ideas for research questions from people with ME/CFS, their Carers, and health care professionals. A survey was launched in May 2021, with an extraordinarily strong response: over 5,300 research ideas were submitted. These were categorised into key themes, which were then summarised into a single overarching question for each theme, producing 59 summary questions. The next stage was to assess whether the summary research questions had already been answered by research. It reflects the lack of high-quality research into ME/CFS that none of the summary questions were able to be ruled out at this stage. People with ME/CFS, their Carers and healthcare professionals were then asked to choose their Top 10 questions from those submitted in a second survey. This ran from October to December 2021 with 1,752 respondents. From the results, the steering group produced a shortlist of 18 questions. Finally, three online workshops were held to finalise the top ten priority research questions from the shortlist of 18. Applications to attend the workshops were accepted from people who had expressed an interest in doing so in the second survey, as well as from the wider public. A total of 36 people were selected, ensuring that all demographics, severity of ME/CFS, and roles were represented. Attendees held small group discussions until the final Top 10+ priorities were identified and agreed.

### **What happens next?**

What the ME/CFS PSP will do ME/CFS PSP is committed to promoting the Top 10+ research priorities as widely as possible. The aim is to publish their findings in a peer reviewed journal. They will promote the Top 10+ through their own networks and continue to promote the power and necessity of patient and public involvement.

### **What Action for ME/CFS will do**

Action for ME commit to progressing research into the Top 10+ and ensuring that people with lived experience are at the heart of all research they support or fund.

They are also actively engaged with the government calling for a nation strategy for ME/CFS that will:

invest in the necessary expansion of capacity in the ME/CFS genetics research field utilise, engage, and invigorate existing research excellence from across the UK and global research community:-

- catalyze and facilitate collaborate and partnership opportunities
- exploit potential for crossover learning from Covid 19 and Long Covid research
- develop funded research programmes on the Top 10+ ME/ CFS research priorities determine. by this PSP.

The ME/CFS PSP has been made possible by funding to Action for ME/CFS from the National Institute for Health Research, the Medical Research Council, and the Scottish Chief Scientist's Office. The list of priority research areas as well as downloadable and audio versions of the project report can be found at [www.psp-me.org.uk](http://www.psp-me.org.uk)

### **Priority 1**

What is the biological mechanism that causes post-exertional malaise (symptoms caused or made worse by physical, mental, or emotional effort, which can be delayed) in people with ME/CFS?. How is this best treated and managed?

### **Priority 2**

Which existing drugs used to treat other conditions might be useful for treating ME/CFS, such as low dose naltrexone, or drugs used to treat Postural Orthostatic Tachycardia Syndrome (POTS)?

### **Priority 3**

How can an accurate and reliable diagnostic test be developed for ME/CFS?

### **Priority 4**

Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition?

### **Priority 5**

Are there distinct types of ME/CFS linked to different causes and how severe it becomes?

Do distinct types of ME/ CFS need different treatments or have different chances of recovery?

### **Priority 6**

Why do some people develop ME/CFS following an infection?

Is there a link with long-COVID?

### **Priority 7**

What causes the central and peripheral nervous systems (brain, spinal cord, and nerves in the body) to malfunction in people with ME/CFS? Could this understanding lead to new treatments?

### **Priority 8**

Is there a genetic link to ME/CFS?

If yes, how does this affect the risk of ME/CFS in families? Could this lead to new treatments?

### **Priority 9**

What causes ME/CFS to become severe?

### **Priority 10+**

Does poor delivery or use of oxygen within the body cause ME/CFS symptoms?

If so, how is this best treated?





# Leger-ME:

[www.danum.me](http://www.danum.me)

## Mutual Support and Signposting Group for people suffering with Fatigue Syndromes \*

Meetings are held,  
on the 3<sup>rd</sup> Thursday  
of each month between  
1pm and 3:30pm  
@ The Linney Centre,  
Weston Road (behind the shops),  
Balby Doncaster DN4 8NF.

1 to 1's sessions are available by appointment only.

For more information contact: Mike at Leger ME, Doncaster

✉ [mike@danum.me.uk](mailto:mike@danum.me.uk) 01302 787353 (Please leave a message)

\*We have a policy of not accepting unregistered calls,  
with all calls being logged.

\* Fatigue Syndromes are long-term health conditions and where Fatigue and Pain are the primary symptoms which include ME/CFS, Post Viral Fatigue Syndrome, Fibromyalgia Syndrome and Post/Long Covid Fatigue Syndrome.

## **Explaining-ME/CFS To Other-People.**

*With Thanks to the ME Association.*

This is a problem many people with ME/CFS encounter. The ME Association have produced an information resource which will help. Here are some examples questions and answers

### **It is difficult when people don't understand ME/CFS They don't understand how you are feeling. How can you explain to them how ill you really are?.**

You could begin by telling people how your illness started and how you feel. Short explanations are best; just tell people the three or four main symptoms you have.

### **So what is ME/CFS?**

ME/CFS is a chronic complex neurological disease where pain and/or fatigue are the prominent symptoms. It is usually triggered after an adverse life event like a infection or trauma, but some case the onset is gradual. It shares many features with other neurological disease like MS, Parkinson's and Arthritis. The main problems are related to the autonomic nervous system with involvement of other body systems. The presentation is very variable and is lifelong and in most cases not progressive.

### **I don't believe in ME/CFS, it's just a psychological illness.**

ME/CFS is actually a physical illness, listed as such by the World Health Organisation. It makes me feel really unwell. Perhaps I could tell you a little about it?

### **You looked alright when you were out yesterday.**

Most people with ME/CFS often look well but I feel ill for much of the time. When you see me out and about, it means I am having a better day! Most of the time you won't see me, I'll be too exhausted to get out.

### **You were well enough to do emails this morning so why can't you cook the tea now?**

Because I've got no energy left, I am exhausted. ME/CFS is a fluctuating condition, I can have good mornings and bad ones. If I do too much then I have to rest or collapse.

### **You would feel better if you did more exercise/you are too scared to exercise.**

I love doing things, always have but people with ME/CFS suffer from what is called post-exertional malaise. It means I feel shattered the day after I've used too much energy. It works better for me to pace myself and to manage my energy levels.

### **I get tired as well but I don't make so much fuss about it.**

ME tiredness is different. Unlike most people, I can still feel tired after a good night's rest.

### **You just don't want to work.**

I love working and going out for a meal and meeting friends. It would be a joy to be well enough to work. Don't forget, it is hard to manage without the money from work and I miss my job very much. *Try to use an image where you can. If, for example, you are asked:*

### **Why are your legs weak and wobbly, you haven't done very much today?**

Because I'm ill my legs have no strength in them. There are 250,000 people like me with ME and they feel weak and wobbly when they have used up their limited amount of energy. People with ME/CFS, especially when they are tired all the time, feel weak and wobbly. At the moment, my legs feel as if I have cycled 10 miles. Another example of using an 'image' is to ask people how they felt when they had flu or another debilitating illness. Do you remember how you felt when you had the flu and how horrible it was? People with ME/CFS feel like that for much of the time.

There will be some people who will never understand ME/CFS. but that is OK! Just tell them you are not well or that you have a debilitating illness. Explain to them, briefly, what you can and can't do together with what help and support you need. Please do call for help if you need more help to explain your illness to your GP, family and friends, we are here to help. See the following reference.

<https://meassociation.org.uk/wp-content/uploads/EXPLAINING-MECFS-TO-OTHER-PEOPLE-AUGUST-2019.pdf>

## So what exactly is ME/CFS?

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a complex multisystem illness that affects the brain and muscle function and, in some cases, other body systems as well. It often causes prolonged ill health and disability.

Although many uncertainties remain about the cause of ME/CFS, research has demonstrated abnormalities involving the brain, muscle, immune and endocrine (hormone-producing) systems. ME/CFS is classified by the World Health Organisation as a neurological disease.

The visible signs and restrictions that people normally associate with being ill or disabled may not always be obvious in someone with ME/CFS. So a person with ME/CFS may look perfectly well and may have no obvious signs of problems relating to either how they can care for themselves or their ability to walk and get about.

ME/CFS is characterised by brain and muscle symptoms that are always made worse by minimal physical or mental exertion – something that is referred to as post-exertional malaise. The severity and range of ME/CFS symptoms varies from person to person. Symptoms and their severity can vary throughout the day, from day to day, from week to week and from month to month. ME/CFS is therefore known as a fluctuating medical condition – a medical term that is particularly important in relation to benefit and other assessments. These symptoms can also, on occasion, vary quite suddenly – so a person's health can deteriorate quite rapidly, leading to complete exhaustion.

## Explaining ME/CFS to other people

If you have been diagnosed as having ME/CFS, it may be of help to take with you something to give to them to help explain your symptoms. This could apply if you are going back to work, going into hospital, off to college or anywhere where you will meet people who will need to know about ME/CFS but may not have a full understanding of this illness.

In a hospital you may well find that some of the staff already know and understand about ME/CFS but at college or work this may not be the case. The ME Association have produced a resource about ME/CFS and a list of symptoms.

## Resources available from the ME Association

The ME Association has 90 leaflets and booklets – have a look at our Order Form at [www.meassociation.org.uk](http://www.meassociation.org.uk) or, ask any ME Connect volunteer for an Order Form.

Some people just don't want to read leaflets about your illness but they may be persuaded to watch a short video.

Look on The ME Association website. The video only just lasts for three minutes but describes how people with ME feel and lists many of the symptoms of ME.

Would you like your GP to understand more about M.E? Here we recommend our clinical guidance book

“ME/CFS/PVFS: An Exploration of the Key Clinical Issues”,

which was written by Dr Charles Shepherd and Dr Abhijit Chaudhuri. I

It can be helpful for the medical profession and indeed your family to read about your particular symptoms, so we enclose a chart for you to complete by noting your own symptoms and the severity of these. A disability rating scale can also help which follows.

There may, however, be one or two people in your life who just don't understand ME/CFS or don't want to believe in the illness.



***The ME Association ME/CFS Disability Rating Scale*****VERY SEVERE**

**100% disabled.** Severe symptoms often on a continual basis. Cognitive function (i.e. problems with short-term memory, concentration, attention span) is likely to be very poor. Bedridden and incapable of living independently. Requires a great deal of supervision and practical support including disability aids, such as a hoist or stair lift with all aspects of personal care (i.e. feeding, dressing, washing) on a 24-hour basis.

**90% disabled** Severe symptoms, often including marked cognitive dysfunction, for much or all of the time. Bedridden and housebound for much or all of the time. Experiences considerable difficulties with all aspects of personal care. Unable to plan or prepare meals. Requires practical support and supervision on a 24-hour basis.

**SEVERE**

**80% disabled** Moderate to severe symptoms for most or all of the time. limited range of physical activities relating to personal care without help. Requires help with meal planning and preparation. Frequently unable to leave the house and may be confined to a wheelchair when up, or spend much of the day in bed. Unable to concentrate for more than short periods of time. Usually requires daytime and night time supervision.

**70% disabled** Moderate to severe symptoms for most or all of the time. Confined to the house for much or all of the time. Normally requires help with various aspects of personal care, meal planning and preparation possibly on a 24-hour basis. Very limited mobility. May require wheelchair assistance.

**MODERATE**

**60% disabled** Moderate symptoms for much or all of the time. Significant symptoms exacerbation follows mental or physical exertion. Not usually confined to the house but has significant restrictions on mobility when outside and may require wheelchair assistance. Likely to require help with aspects of personal care and meal preparation but not necessarily on a full-time basis. Requires regular rest periods during the day. Unable to resume any form of meaningful employment or education on a regular basis.

**50% disabled** Moderate symptoms for much or all of the time. Symptom exacerbation follows mental or physical exertion. Not usually confined to the house but mobility restricted to walking up to a few hundred yards at best. May require help with some aspects of personal care. May require help with meal planning and preparation. Requires regular rest periods during the day. Able to carry out light activities (ie housework, desk work) associated with normal daily living for short periods but not able to resume regular employment or education.

**40% disabled** Mild to moderate symptoms for some or much of the time. Normally able to carry out most activities associated with personal care and normal daily living but may require assistance with meal preparation. May be able to cope with some work-related tasks for short periods provided they are not mentally and physically strenuous but not able to resume employment on a regular basis.

**MODERATE TO MILDLY AFFECTED**

**30% disabled** Mild to moderate symptoms for some of the time. Normally able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short distances on a regular basis. May be able to return to work on a flexible or part-time basis provided adjustments are made to cope with cognitive and mobility problems. May have to stop leisure or social pursuits in order to return to work or education.

**20% disabled** Normally only mild symptoms at rest but exacerbation will follow activity. Able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short to medium

# Eat well, spend less

Healthy eating is important and doesn't need to be expensive. This Food Fact Sheet will give you some ideas to help you to eat well and keep costs down.

## Top tips to save money when shopping

Follow these tips when you go shopping to help you spend less:

1. Make a meal plan, particularly for your main meals
2. Write a shopping list and check what food you already have at home to avoid buying things you don't need
3. Select a time to shop in the week when you are not in a rush
4. If you can, avoid shopping on an empty stomach as it may affect what and how much you buy. Consider shopping after you have eaten
5. Be aware that special offers are not always the cheapest option (See 'How to read a label')
6. Ask a member of staff at your supermarket for fresh food reduction times and try to shop then for reduced priced items. Avoid purchasing more than you need or can store. Use within the specified date or freeze for later
7. Value brands often taste just as good for a lower price
8. Local food markets offer locally-sourced foods which are usually good value for money
9. Cheaper products are not always at eye level or positioned obviously. Check out all the shelves (including top and bottom)
10. Larger supermarkets offer a better range of produce, often at a cheaper cost, so do your main shop there if you can

## How to read a label

When deciding which product to buy, use the unit pricing to check the price of a food for a specific unit of weight (or volume). It helps you select between products when the product size is different, or if one product is on a 'special offer'.

## Understanding unit pricing

Cornflakes Cereal 720g - £2.40    £0.33/100g	Cornflakes Cereal 1kg - £3.00 <b>£0.30/100g</b>
Chicken Breast 300g - £1.80    £6.00/kg	Chicken Breast 650g - £3.80 <b>£5.85/kg</b>
Braeburn Apple five pack 670g - £1.60    £2.39/kg	Braeburn Apple Loose <b>£2.20/kg</b>

Unit pricing can help you get better value for money, but remember to still only purchase what you need to avoid wasting your food and your money.



Label showing price per KG

## 5-a-day on a budget

This section shows you how to achieve five portions of fruit and vegetables a day on a budget:

- Select seasonal fruits and vegetables as they are widely available and less expensive, for example strawberries in summer and parsnips in winter
- Consider loose produce, for example loose apples are often cheaper than the packaged variety (See 'How to read a label')
- Some supermarkets sell 'wonky' fruit and vegetables which are just as nutritious but vary in shape and size - so cost less
- Tinned fruits and vegetables are cheap and quick options to add to meals. For example, a portion of baked beans is one of your 5-a-day and a source of protein. For a healthier choice choose fruit canned in natural juice rather than syrup and vegetables canned in water without added salt
- Frozen fruits and vegetables can be good value and highly nutritious as the nutrients are sealed in during the freezing process. They are also pre-prepared which makes cooking quicker and easier. Try adding some to your meals, for example, add berries to your porridge or peas to your rice





- A small, cupped handful (30g) of dried fruit is a portion and can be added to your cereal or salad, for example raisins or apricots
- Visit a local allotment or community garden as they may have cheap fruits and vegetables for sale

### Budget meal ideas

Meal	Ideas
Breakfast	Value cereals, milk and a portion of dried fruit Porridge oats soaked overnight with yoghurt and frozen berries Hot porridge topped with dried fruit Eggs, baked beans or nut butter on brown toast Cheese and vegetable omelette
Lunch	Egg or cheese spread or cheese and cucumber sandwiches Homemade or tinned soup with brown bread Tinned fish on toast or in a sandwich served with salad Jacket potato with baked beans, cheese, cottage cheese or tinned fish with salad
Evening meal	Veggie burger with homemade potato wedges and frozen peas Cottage pie served with peas and carrots Chicken and vegetable stew with Jollof rice or couscous Tuna and sweetcorn pasta bake Vegetable curry and rice Rice and peas with mackerel in tomato sauce
Pudding	Tinned or seasonal fruit served with yoghurt Homemade apple crumble and custard Rice pudding with jam
Snacks	Malt loaf with low fat spread Carrot, cucumber or celery sticks with hummus Cheese and crackers Boiled egg Sliced apple with peanut butter Microwave popcorn

- Replace protein sources with alternatives, for example, add chickpeas to curry or baked beans to shepherd's pie
- Good value protein sources include: baked beans, tinned mixed beans, tinned chickpeas, lentils, some meat substitutes, milk, yoghurt, hummus, hens' eggs, frozen chicken thighs, budget cuts of meat, tinned fish (especially sardines and mackerel) or frozen fish
- Prepare a homemade packed lunch, for example leftovers from the night before or a sandwich
- Have a stock of herbs and spices to add flavour to meals or side dishes. Mixed herbs are good to add to most savoury dishes
- Freeze excess food, such as bread and other perishables. Most foods can be frozen, so look at the packaging for guidance
- Consider bulk or batch cooking meals if you can (make a large amount and split into portions). Freeze or refrigerate leftovers for convenience and to save money

### Further Information

If you are struggling to afford food and would like support, these are organisations that can help:

**Citizen's Advice** can help you understand what support you may be entitled to and make the most of your money

**Food banks** supply free food to people that are struggling financially. Search the Salvation Army or Trussell Trust website for your closest food bank. Usually, you need a referral for a Trussell Trust food bank (for example from a social worker, health care professional or school). To find a local independent food bank you can contact ifanconnect@gmail.com. Some independent food banks require a referral.

If you are pregnant or have young children, you may be eligible for Healthy Start Vouchers and can apply online or by post.

### Cooking tips and reducing food waste

Cooking from scratch can be cheap, fun and builds your confidence! Follow these tips below:

- Make your favourite takeaway food at home, for example curry and rice or stir fry with noodles
- Make homemade soups from leftover vegetables
- Leave fruit and vegetable skins on wherever possible and suitable. If peeling is required, some peelings can be added to recipes like soups or stews
- Reduce your meat portions and consider having a meat free meal or day at least once per week

### Top tips

1. Make a meal plan and plan your shopping trips
2. Look for cheap and convenient ways to get your 5-a-day
3. Read the label to make sure you are getting the best value for money
4. Use food 'waste' such as peel to flavour soups and stews
5. 'Batch cook' where possible

If you are having difficulty eating healthily on a budget, ask your GP, speak with a dietitian, or contact the support organisations listed above.



This Food Fact Sheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian.

If you need to see a dietitian, visit your GP for a referral or [bda.uk.com/find-a-dietitian](http://bda.uk.com/find-a-dietitian) for a private dietitian.

You can check your dietitian is registered at [hpcp-uk.org](http://hpcp-uk.org). his Food Fact Sheet and others are available to download free

This resource has been produced by the BDA in partnership with Dietitians Alexandra Harper, Hannah Johnston, Isabel Rice and Avril Aslett-Bentley.  
The information sources used to develop this fact sheet are available at [bda.uk.com/foodfacts](http://bda.uk.com/foodfacts)

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## ***A Dietitians' top tips to eat well on a budget***

*With thanks to the British Dietetic Association dated 12th Oct 2022.*

With the cost of living crisis meaning that people are looking for ways to save money when shopping, the team at Dietitian Fit & Co looks at ways to eat well on a budget.

### **Plan meals:**

Planning in advance helps to reduce costs, ensuring that you can buy what you need. If planning for a whole week seems like too much right now, start off with two or three days. Buy only what you need and know you will use to prevent any food waste.

### **Shop with a food list:**

This goes hand-in-hand with planning meals – create a list of all the ingredients that you need and stick to only what is on the list! Again, this means you are less likely to buy foods or drinks you won't use and be more mindful about your spending overall. Spend a moment to also check what you have in your cupboards already, so you buy something that you already have!

### **Look at supermarket brands:**

Often premium food brands are marketed to make you believe they are superior in taste and quality. However, that isn't always the case! Try out more supermarket-branded products – you may even be surprised by the taste. Often these are less than half the price of the branded version. In some cases, they are also more nutritious, and can even contain less sugars, salt, and saturated fats too. Try different products each week and find what you like.

### **Reduce waste:**

One sure way to help with your budget is trying to minimise food waste. If you have leftovers, turn these into different meals, with the addition of a few more ingredients. For example, leftover roasted veggies can be used in a pie, omelets, stir fries or made into a soup. Look out for expiration dates – if you know you won't get a chance to use the product before it expires, can you freeze it? Keeping a list of expiration dates stuck to the fridge can be very helpful!

### **More vegetarian meals:**

Vegetarian meals can be significantly cheaper than when using meat or fish products. Using dried or tinned beans and lentils or eggs as protein alternatives can be delicious – but if you are not so keen, how about substituting half the meat in recipes for something such as lentils. This works well in a curry and chilies, or soups and stews.

### **Use frozen or tinned fruits and vegetables:**

Frozen and tinned fruits and vegetables are just as nutritious, if not more so, than the fresh varieties. They also usually come ready chopped and are less than half the price! Great to use when you are short on time too or eating foods outside their season. For example, add a handful of frozen peas, carrots, peppers, onion, or cauliflower to meals for quick vegetable additions. This will also help reduce food waste as frozen products have a much longer shelf life than fresh. NB. Just be mindful of tinned foods stored in syrups or juices, due to sugar content.

### **End-of-the-day discounts.**

Often supermarkets will cut the prices of products towards the end of the day if they may be expiring on that day. This means great discounts for higher-priced items! If you get any meat or fish items, they can be frozen on the day and used at a later date if you are not having them on that day. This also applies to ready-prepared meals, which are often suitable to cook from frozen too.

### **Cook smarter:**

Using a slow cooker to produce meals can be cheaper to run – it is estimated to be 16p per day for energy\*, versus the average oven at 87p per day\*. You can make multiple portions of food in a slow cooker, to be frozen for future meals. Air fryers are also great to produce crispy meals using less oil, and these are estimated to be around 14p to run per day\*. But if you need to use the oven, make sure to use it to cook multiple items at once for maximum benefit.

\*Research on costs carried out by supplier Utility and supermarket Iceland.

## Recipe Corner

### 1. AUBERGINE & CHICKPEA CURRY

Serves 4. Estimated preparation time 15 mins.  
Cooks in about 45 minutes

#### Cooking method

- 1) Mist a large pan with the spray and fry the onion over a medium heat for 6-8 minutes until soft.
- 2) Add the garlic and ginger, cook for 1 minute, stir in the spices and cook for another minute.
- 3) Stir in the puree and cook for 1 minute. then add the aubergines. passata and stock.
- 4) Bring to a simmer and cook for 25 minutes. adding the chickpeas for the final.
- 5) Stir in the yogurt. Lemon zest and juice and coriander.
- 6) Add the cooked rice to the bowls. and top with the curry, the extra yogurt and coriander. serving the limes on the side.

*You could substitute new potatoes for aubergines*

### 2. CHICKEN & VEGETABLE PAELLA

Serves 4. Estimated preparation time 20 minutes.  
Cooks about 25 minutes

- 1) Put a large frying pan or wok over a high heat and mist with cooking spray.
- 2) Add the chicken and cook, stirring, for 3 minutes until golden.
- 3) Reduce the heat, add veg and paprika and cook for 2 minutes.
- 4) Add the rice and thyme, stir in the tomatoes and stock, and season.
- 5) Simmer for 15-20 minutes and stir occasionally, until the rice is cooked.
- 6) Scatter over the parsley, and serve with a lemon half for squeezing over.



#### Shopping list 1

Cooking oil spray  
1 red onion, finely sliced  
3 garlic cloves, crushed  
1tbsp grated fresh ginger  
1tbsp curry powder  
112tbsp ground coriander  
3 cardamom pods, crushed  
1 star anise  
1tbsp tomato puree  
2 aubergines, cut into 3cm chunks  
500g passata  
300ml veg stock, made with a reduced salt stock cube  
2 x 400g tins chickpeas, drained and rinsed  
50g fat-free natural yogurt, plus 2tbsp to serve  
Finely grated zest and juice of a lemon, plus wedges to serve  
2tbsp finely chopped fresh coriander, plus extra to serve  
2 x 250g pouches microwave brown basmati rice

#### Shopping list 2

Cooking oil spray  
2 x 165g skinless chicken breast fillets, thinly sliced  
1 red onion, roughly chopped  
1 red pepper, deseeded and roughly chopped  
1 carrot, finely chopped  
1tbsp smoked paprika  
300g paella rice  
2 sprigs fresh thyme  
400g tin chopped tomatoes  
1 litre chicken stock, made with 1 reduced salt stock cube

#### TO SERVE

Handful fresh flat-leaf parsley and lemon halves

**What is ME?***With thanks of ME Research UK*

ME/CFS is an illness affecting many different parts of the body, and which can last for a long time in some people. The main symptoms are:

- Intense fatigue and a feeling of being unwell (post-exertional malaise) that is not improved by rest, and can be worse after physical or mental effort;
- Pain in the muscles or joints;
- Problems in the stomach or intestine;
- Difficulty sleeping; and
- Memory or concentration problems (cognitive dysfunction).
- Other less-common symptoms include headaches, sore throat and difficulties with vision.

Different people experience different combinations of these symptoms, and they can also vary in severity between individuals. Unlike the tiredness experienced by healthy people, the fatigue associated with ME/CFS can happen after even mild or moderate effort, and may occur hours or days afterwards.

There have been many names given to the illness over the years, but at the moment the most widely recognised are myalgic encephalomyelitis (ME) and, separately, chronic fatigue syndrome (CFS). Each has a separate history and differences in main symptoms. However, many healthcare systems, healthcare professionals and researchers commonly use the term ME/CFS – and that is why many charities do so also.

It is important to remember that differences in the name do not change the lived experiences of those affected by illness. ME and CFS are recorded separately by the World Health Organisation, with both being classified as diseases of the nervous system.

**What is the cause?**

The cause of ME/CFS is not yet known. In some people the illness develops gradually over months or years, while in others it appears to be triggered by a viral or bacterial infection. Herpesviruses, enteroviruses and Q fever have all been suggested as possible triggers of ME/CFS. More recently, people with chronic illness following COVID-19 have reported symptoms similar to those associated with ME/CFS. One important question is why ME/CFS happens in some people but not in others, and research studies continue to look for differences in the genes that may explain this.

**Living with ME/CFS**

ME/CFS affects an estimated 250,000 people in the UK and over one million people in the USA – this is more than the number with HIV infection or multiple sclerosis. The physical symptoms vary in severity between individuals, but can be as disabling as multiple sclerosis, congestive heart failure and other chronic conditions. The course of the illness can also be variable: some people improve quite quickly, while others develop chronic illness lasting many years. The illness touches all social groups and all ages, including children, and women are more likely than men to be affected.

ME/CFS can have a big impact on a person's ability to carry out normal activities, including everyday tasks, keeping a job, going to school, and taking part in family and social life. Many people with ME/CFS are unable to work fulltime, and up to a quarter are house- or bed-bound.

**The role of ME Research UK**

None of us at ME Research UK are medically qualified, and so we are not in a position to offer any specific advice or help on treatments.

ME Research UK exists to fund high-quality biomedical research into ME/CFS – to find its cause, develop effective treatments, and ultimately to discover a cure.

Thanks wholly to the support of donors, to date we have provided over £2 million of funding for more than fifty research projects around the world, but there is still much more to do.

If you would like to help support further research into ME/CFS, please consider fundraising for ME Research UK or making a donation to the charity, so that we can continue to inform, influence and invest in ME research.  
More information about ME/CFS



## How is ME/CFS diagnosed?

A positive diagnosis of ME/CFS can only be made by a suitably qualified medical practitioner such as a GP or hospital consultant. In the UK, most people seeing a doctor in the NHS are diagnosed using the NICE guidelines. As there is no specific laboratory test for ME/CFS, a diagnosis is based on a person's medical history and pattern of symptoms. Importantly, other diseases that cause similar symptoms must be ruled out before ME/CFS can be diagnosed. Unfortunately, misdiagnosis is common.

According to the NICE guideline, ME/CFS can be suspected if ALL of the following conditions are met:

- a person has had persistent symptoms (listed below) for at least 6 weeks in adults, and 4 weeks in children and young people, and
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels, and
- the symptoms are not explained by another condition.

ALL of the following symptoms should be present to suspect ME/CFS:

- Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- Post-exertional malaise after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer.
- Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.
- Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

Other symptoms can also be associated with, but are not exclusive to, ME/CFS:

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position
- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold
- neuromuscular symptoms, including twitching and myoclonic jerks
- flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches
- intolerance to alcohol, or to certain foods and chemicals
- heightened sensory sensitivities, including to light, sound, touch, taste and smell
- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion.
- What treatments are available?
- There is not yet any treatment that can cure ME/CFS.

Until a cure is found, there are a number of approaches that can help people manage their illness, although it is very important that these are discussed with a GP beforehand. Drug treatments are available for some of the specific symptoms of ME/CFS, such as sleep disturbances, pain, headaches, abdominal symptoms and balance disorders. Many people with ME/CFS find that managing their activity – by pacing or other methods – helps them to live with the illness day to day, and a variety of coping strategies are available that can make a real difference.



## ***Bentley Park Doncaster Lilly Pond in Autumn.***

In the Summer issue of 2021, we featured on the front page a picture of the Lilly pond in Bentley Park. During that summer the pond gave pleasure to many people as it has done over the years since restoration. However, the summer of 2022 was completely different. Due to the very hot weather, a lot of water evaporated, and the levels went down by several feet. There was a severe algae overgrowth which poisoned the water and most of the fish died.



Because of the school holidays children started to play in the Lilly Pond, which is around six feet deep in the centre, it was fenced off. The pond was drained and everything in it except the plants was removed. Over a few weeks, the fountain was repaired, and the pond refilled. In late September to my surprise, I found that it has been restocked with goldfish. I frequently visit Bentley Park because it is flat.



*The Lilly Pond in Summer 2021*



*If you do walk around the pond, the goldfish follow you round in a shoal.  
What I am not sure about is who feeds them ?*



*Around the pond are trees, some of which have displayed deep Autumn colour. There is also a Cafe that sells refreshments.*



*Looking to the South end of the Park. Many people frequently stop to watch the fishes.*



## North of Doncaster and South of Wakefield

*Personal Comment from Trevor Wainwright.*

There is a road that passes through Wakefield, the A61, which connects Derby and Thirsk in North Yorkshire by way of Alfreton, Clay Cross, Chesterfield, Sheffield, Barnsley, Wakefield, Leeds, Harrogate, and Ripon. It holds special memories for me as it was the route, I used to take to what I used to call the North part of The Dales. I would hitch hike to Ripon then head West. South was the route we used to take to Sheffield Speedway. When I got a motorbike and was a learner, I used to take it to Derby then continue to Coventry to the speedway there. I did so even when I passed my test, it was a more interesting ride than the motorway. I still use it or did when going to poetry events in Sheffield after joining it at Jn 36 on the M1.



*Newmillerdam Country Park is open every day. It is located 3.5 miles south of Wakefield, on the A61 (Barnsley Road), Newmillerdam Country Park features a central lake surrounded by a surfaced path with surrounding broadleaved and coniferous woodland located on the slopes. The postcode WF2 6QP for Newmillerdam is approximate but can be used with satnavs and route finders."*

So, as it passes South through Wakefield, we leave the city behind as we go through Sandal, with open country to the right, the road bends to the right and passes by a stretch of water known as Newmillerdam (more on that in the next issue) at the end of which is a car park, with its obligatory ice cream van. One day during the pandemic when we were allowed out, I called there intending to have a walk round the lake. It had been a long time since I had been there, and it was now known as Newmillerdam Country Park.

My attention was caught by the sign "Gnome Roam." According to the info it is a themed family adventure walk within the woodland which is 1.8 miles long and is buggy-friendly if you do not mind a push up a hill! A simple walking trail encourages children to use signs and clues to spot carved statues of gnomes and wildlife. Created as an added attraction to the already beautiful Newmillerdam Lake, great care and thought had been put into it. Sadly, there was no information about how it all started, which was disappointing as it always helps me to tell a better story on my Facebook album "My Beloved Yorkshire."



The task is to follow the route to find the different gnomes who have scattered around the woodland in their attempt to escape the bear! So, it was decided, it would be 'The Gnome Roam' following the signs and looking out for the gnomes, their jobs on the roam, plus finding out there are activities to do at each one, such as look for wildlife and use the magnifying glass to inspect creepy crawlies.



The Gnome Roam also boasts an Arboretum, where another task is to find three dinosaur trees. They are being The Maidenhair Tree from Japan, Dawn Redwood, and Monkey Puzzle, I found them all except for the Dawn Redwood. Other trees of interest are also labelled, some actually appearing to have faces, so you can use your imagination as to what they remind you of.

On finding each carved gnome there is a notice saying who they are and what they are responsible for. One thing not to miss is finding Bruin the Brown Bear, famous for 1847 for escaping from a menagerie situated in Newmillerdam Woods. The storyboard tells of how it took 40 minutes to recapture him, and the antics of the pursuers and what befell them. The woods are also used for outdoor activities such as building shelters out of fallen branches from the trees, there are a few in various stages of construction, one even referred to as a Gnome Home.



So off I went on a cool but pleasant March day. The first Gnome I was supposed to find was Gnome Tony, The Park Ranger, but it seemed like it was his day off, maybe he had been taken for some maintenance. Then it was Gnome Alan: Tree Warden, sat astride a woodland creature, walking past a young tree called "Ailanthus altissima" or Tree of Heaven supposed to have medicinal properties, it may have as I noticed daffodils growing at its base. I saw no others on the rest of my walk, no doubt they would soon be there. Insects are referred to as minibeasts who live in the minibeast zone, along with a board of what minibeasts you can find. They are favourites of Gnome Robert of



whom it is said loves exploring the minibeast zone; his carving shows him with book and magnifying glass, as if doing as such. Gnome Don the supervisor was next, but he has his back to the path and is crouched as if playing bowls, and he is watching something with interest, Bruin the Big Brown Bear. Next to Bruin is the full story of his escapade on the night in 1847, as it featured in the Wakefield Express. Following on from reading of Bruin's humorous escapade, we are met with Gnome Geoff carved holding grass cutting shears, responsible for keeping the paths clear. After Gnome Geoff comes Lawns Dike and a welcome rest on a bench with braille on the back rest, letting visually impaired know where they are, I had the company of a beautifully carved owl.

Then it was onward to Lawns Dike, itself a stream that runs into the Southernmost part of the main lake, in what is known as Lawns Dike Valley, situated between Kings Wood to the North and Bushcliffe Woods to the South, it is also where we meet Gnome Richard, The Fisherman, complete with net and catch. The circular walk between called Lawns Dike Trail started in January 2012 by Friends of Newmillerdam Country Park and opened in Summer 2013 is wheelchair friendly consisting of a boardwalk, viewing area and picnic area all made from recycled plastic, with seats at the wheelchair passing places, and beginning and ending at a small bridge that crosses Lawns Dike. At the start, the picnic area is ideal for a cuppa before starting and a more rewarding cuppa on completion. The plants and trees in the valley are all native species suitable to the boggy conditions.

Following the trail, I was sad to see that some dog owners had left poop bags at the side of the path, this meant more





work for the next gnome, Gnome Peter, the litter picker. As you walk along the path, for the more energetic there are log bridges across the dike. Towards the end of the walk, the last gnome we see is Gnome John, The Woodcutter, chainsaw (not a real one) at the ready

At the end of the walk, you can continue off the trail going further into the valley or turn left or right depending on which way you took and go back to the picnic area. I decided to go up the path through Kings Wood, although when you get back to the bridge and turn left you can follow the lakeside path back to the car park.

One last look through the trees, and back the way I came through the Gnome Walk Arboretum where passing the Monkey Puzzle Tree I made my way back to the car park and drove home to download my photos into my Facebook album "My Beloved Yorkshire Part 2."

In the next issue, my return, a walk round the dam itself and beyond with a few childhood memories thrown in.

