

Prescription charges for adults...

Having access to a broad variety of low protein products is essential for individuals with PKU following a restricted phenylalanine diet. In the UK, the vast majority of specialist low protein foods are available on prescription, and can be dispensed through local pharmacies or using home delivery services. All children are exempt from payment of prescription charges, but this exemption status may change in adulthood which can lead to confusion and expensive fines.

Building on the fantastic article by Barbara Cochrane in the previous issue and recent tightening of the rules in the NHS, we have chosen to look at prescription charges for adults with PKU following a low protein diet.

Whilst medical foods are not officially medicines, it is recognised that their use must be with medical supervision and are therefore considered “borderline substances” which must be prescribed by a doctor. With the increase in range, number of foods available on prescription and scrutiny of GP budgets, come associated problems for patients in obtaining sufficient supplies to meet their needs.

Prescription charges:

Charging for prescriptions began within 10 years of the National Health Service being established, with the first charges introduced in 1952.

The main aim of charges is to offset the cost of medications, although it has been argued that this is at odds with the “free at the point of use” ethos on which the NHS was created.

In 2016, the prescription charge for each medicine dispensed in England increased to £8.40, an increase of 20 pence from the previous year. Charging for prescriptions does generate income for the NHS, although it is believed to be less than 1% of the total amount spent by the NHS per year. With high expectations of increasing efficiency savings, there is a reluctance to abolish charges altogether in England (as has happened in Wales, Scotland and Northern Ireland).

Exemption from prescription charges:

Everyone should be able to access medications they need, and prescription charges should not prevent someone from receiving treatment. To address this, certain criteria were developed which mean some people are exempt and not expected to pay any prescription charges for their treatment. The main criteria include age, health and income.

According to the Department of Health, 90% of prescriptions are dispensed free of charge. Certain medications, such as prescribed contraceptives are exempt from prescription charges.

Medical exemption:

If someone has a health condition that qualifies for medical exemption, they do not have to pay any prescription charges. You need your GP to sign a form confirming you have a condition that makes you exempt, and you will be issued with a medical exemption.

- a permanent fistula (for example, caecostomy, colostomy, laryngostomy or ileostomy) which needs continuous surgical dressing or an appliance;
- a form of hypoadrenalism (for example, Addison’s Disease) for which specific substitution therapy is essential
- diabetes insipidus and other forms of hypopituitarism
- diabetes mellitus, except where treatment is by diet alone
- hypoparathyroidism
- myasthenia gravis
- myxoedema (that is, hypothyroidism which needs thyroid hormone replacement)
- epilepsy which needs continuous anticonvulsive therapy
- a continuing physical disability which means you cannot go out without the help of another person
- cancer and are undergoing treatment for:
 - cancer
 - the effects of cancer
 - the effects of cancer treatment

PKU and prescription charges

Adults with PKU living in England are not medically exempt from prescription charges. This is because PKU is not currently a condition that qualifies for medical exemption from prescription charges, nor has it ever been. This is an important point,

Table 1: Prescription exemption categories

Reason for exemption	Who is exempt?	How can I prove it?
Age exempt	Children aged under 16 Adults aged over 60	Date of birth should be present on prescription
Exemption for students	Those aged 16, 17 and 18 in full-time education *apprenticeships not eligible	Date of birth on prescription plus either a letter from your school/college or student card
Exempt due to receipt of certain state benefits	Those in receipt of certain state benefits (e.g. Universal Credit, certain tax credits *DLA/PIP not eligible)	NHS tax credit exemption certificate or valid entitlement letter from Job Centre Plus
Exempt on maternity grounds	Pregnant women and women who have had a baby within the past 12 months	Maternity exemption certificate
Exempt on medical grounds	See section below	Medical exemption certificate

...what you need to know

as recently the NHS Business Authority has become far stricter at checking if people are exempt. Many people may believe they do not have to pay prescription charges because they have PKU, and some adults may never have paid prescription charges before.

We may question why PKU is not on the exemption list – it is a rare medical condition and lifelong dietary treatment is recommended. Phenylalanine-free supplements and medical foods required are only available on prescription. There was a recent petition campaigning for PKU to be added to the medical exemption list. Whether this will change in future is uncertain, so for now we can only focus on ensuring adults are not hit with financial penalties.

What should I do?

If you are an adult with PKU living in England, it is important to check if you are exempt from prescription charges for non-medical reasons (such as income or pregnancy). Your GP cannot issue you with a medical exemption certificate because of PKU.

If you have one of the conditions on the medical exemption list in addition to PKU, you do not have to pay any prescription charges but you do need a certificate. However, if you do not have any of these conditions and are not exempt on other grounds, you will need to pay prescription charges.

For the majority of people with PKU, a prepayment certificate (PPC) is the cheapest way to pay prescription charges. For a set price, you can buy either a 3 month or 12 month certificate which covers all prescription charges. If you regularly collect 4 or more different items (such as your amino acid supplement, milk, bread and pasta) on prescription each month, you will save £300 using a PPC. Once you have a PPC, any other medications you might need (such as antibiotics) will also be covered.

For the past few years, the cost of the PPC has been frozen (unlike individual prescription charges). The current cost is

Potential savings with a prepayment certificate		
Number of medicines/medical food items used each month	Saving with a 12 month PPC	Saving with a 3 month PPC
3	More than £195 in 1 year	At least £45 over 3 months
10	More than £900 in 1 year	At least £175 over 3 months
15	More than £1400 in 1 year	At least £345 over 3 months

£29.10 for a 3 month certificate, and £104 for a 12 month certificate. You can pay in one payment, or if you buy a 12 month PPC you can pay in 10 monthly instalments by direct debit to spread the cost. You can buy a PPC online, or some pharmacies are able to sell them.

If you are unsure if you are exempt or are waiting for your PPC, it is best to pay all prescription charges which can then be refunded at a later date once you have confirmation of your exemption status or PPC5. Make sure you ask your pharmacist for a refund form (FP57) at the time you pay the charge, as you cannot ask for one at another time.

For women with PKU who are pregnant, your GP can issue you with a maternity exemption certificate which will mean you do not need to pay prescription charges

throughout your pregnancy or until your child reaches 1 year of age.

If you are not exempt but have a low income and are worried you cannot afford to

pay for prescriptions, you can also apply for help through the NHS Low Income Scheme⁸. This is available if your annual income is less than £16,000. You need to complete a HC1 form providing details about your income, and may be given a full (HC2) or partial help (HC3) certificate to help with costs, including prescription charges.

If you use a home delivery service (such as Nutricia Homeward, VitaFlo at Home or Dial-a-Chemist) you should also inform them of your pre-payment certificate number, or provide them with the reason you are exempt.

Not paying for prescription charges if you are not exempt is classed as fraud. The current fine for not paying a prescription charge is £100, plus the full cost of prescription charges for that prescription (£8.40 for each item). You will be expected to pay the fine even if you made a genuine error and did not realise at the time you were not exempt from prescription costs. ■

Checklist: How to avoid risking a fine

- Check if you are exempt from prescription costs – speak to your pharmacist, check online (www.nhsbsa.nhs.uk/HelpWithHealthCosts.aspx) or contact the NHS Business Services Authority
- If you are exempt, make sure you have a valid exemption certificate or acceptable letter and that this is up-to-date
- If your circumstances change (related to income or maternity status) make sure you recheck your exemption status
- If you are not exempt, consider buying a prepayment certificate (PPC) as this is often the cheapest option
- If you are concerned about prescription costs, consider applying to the NHS Low Income Scheme for support with healthcare costs
- Make sure you show your exemption card to your pharmacist whenever you collect your prescription items, and give the exemption reference number to any home delivery companies you use
- Keep your PPC up-to-date

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