

Preparing for the future



Care

Parents usually worry about "what will happen when I've gone or when I am too infirm to carry on caring?"

If there are no relatives willing to care for your son and daughter, their care will transfer to your local social services department. If you already have links with social services and have had assessments for your son or daughter, they will find it much easier to

place them in appropriate care.

If you have had no previous links, they may make assessments which are based on their perceived needs, rather than the more complex needs which you as a parent could have told them about.

It is essential, therefore, that if you do not currently have links with social services, you should request an assessment, just so that they are aware of your son or daughter's existence - even if you do not currently require help.

Power of Attorney

You may wish to consider Power of Attorney, either for making decisions on behalf of your son or daughter with PWS (it also gives you legal rights to be at meetings with professionals on their behalf), or to give to a relative on your behalf, should you become unable to care for your son or daughter's welfare in the future. Find out more at

<https://www.gov.uk/power-of-attorney>

<https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney/>

Mencap also has resources and discussion groups on this topic
<https://www.mencap.org.uk/>

Legacies

If you are writing or rewriting your will, please consider leaving a legacy to the PWSA UK. You can either leave a set amount, or a proportion of your estate - the latter is sometimes preferable as it allows for variations over time in the total value of your estate.

Your legacy will help us to provide a brighter future for people with PWS by continuing our work with those who have no one else to speak for them. It will also help us to support families who still coping with the challenges brought by PWS.

If we have helped you in the past, please help us to improve the future for everyone with PWS.

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Wills and trusts

Even if you are still quite young, it makes sense to make a will now that sets out the specific care plans you have for the person. Not only that, but you could also leave instructions for the person or organisation who takes care of the person after you have gone to become a member of the PWSA UK - that way, we don't lose touch with the person with PWS and can continue to support them.

However, when making a will, there are various pitfalls to be wary of, including leaving money and property directly to the person with PWS. Depending on how much you leave, some of it will be used by social services to pay for their care. A solicitor with a knowledge of leaving money to people with learning disabilities can advise you on the best way to avoid this - setting up a Trust Fund is the usual route.

You can find more information about this in the leaflet, **Making a will and setting up a trust** <https://www.pwsa.co.uk/assets/files/making-a-will.pdf> which is enclosed with this pack.