

what is home care?

Homecare is a service provided to patients to enable them to receive treatment with Enzyme Replacement Therapy (ERT) away from the hospital, in their home, or another suitable setting such as school or work. Treatment with ERT at home has been carried out successfully and safely in the UK for more than 15 years and is usually less stressful and more convenient than hospital based therapy. The infusions at home are initially carried out by Homecare nurses, who have received specific training in delivering an enzyme replacement therapy, but over time patients and families may choose to receive training, so that they can do their own infusions independently.

Whilst this might seem quite daunting at first, it is much easier than you might think and there are many advantages including greater flexibility around when the infusions can occur and allowing you to still have infusions whilst you are travelling/away from home. Full training can be provided to support you, a friend or a member of your family in giving the infusion on your own, although there will always be a nurse available on the end of the phone if you have any difficulties.



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Within the UK the NHS provides homecare under what is known as a framework agreement that manages the provision of homecare throughout the country. This framework allows you to access different levels of homecare depending upon your needs:

Dependent: a nurse will carry out intravenous access (cannulate or access an implanted venous access device i.e a vascuport), make up the ERT, administer the infusion, and remove the device at the end.

Semi-Independent: a nurse can support you with your infusion by either carrying out venous access (cannulating or accessing an implanted venous access device) and/or makes up the infusion, but you administer the infusion and remove the cannula/ vascuport needle at the end

Independent: the homecare nurse does not attend the infusion visit, as you are able to do this yourself, but visits intermittently every 6 months- 1 year to support ongoing training.

The Homecare Company will provide telephone on call support and will deliver all the medication and the ancillary items you will need. They liaise closely with the Clinical Nurse Specialists at your specialist centre. You can move through the levels of dependency described above at your own pace, as you become trained and competent. You may also increase the level of input you need if your health or circumstances change.

If you are prescribed the oral (Cerdelga or Zavesca) Substrate Reduction Therapy (SRT) you will receive regular deliveries of this from the Homecare Company and will be telephoned in advance of a delivery to ensure there is enough medication delivered

Homecare companies may change from time to time but all of those used have to demonstrate their ability to provide a good service.

You will need to be at home to receive your deliveries and to have your infusion if the nurse is doing this for you. You will also need to keep in touch with the homecare customer services team who will arrange your deliveries and ensure you have enough of everything you need.



Do talk to your Specialist team about which level of service is right for you and let them know if you are having any difficulties with the service you receive.