



Little Hearts Matter

Supporting every step of the half a heart journey

Points to raise at a **DLA** or **PIP** face to face **appeal**

Many of our members have asked to see examples of the evidence we write to support people with their DLA or PIP appeals. The information below is to provide examples only – we do not advise you copy this information word for word, but it should help you to better understand how to put things into words.

- Explain the heart condition in detail including the fact that it is not correctable.
- Talk about Fontan created complications such as medication and ongoing treatment – anticoagulation and cardiac medication are very important as they are recognised as treatments for single ventricle heart disease. Include letters from the hospital where they describe the treatment and challenges.
- Talk about any other medical conditions and care needed
- Talk about reduced energy levels and how they are balanced. How decisions have to be made about where the energy is used to maximise each day. Include exercise tolerance test results.
- Circulation – reduced ability to keep warm, leg pains, headaches/migraines
- Mobility – What added care has been put in place for mobility? Always explain that a child or adult can walk (if they can) but that they have problems maintaining exercise. Do they have a wheelchair?
- Daily life – describe added care needed with everyday life. What should they be able to do independently at their age? Childhood - washing, helping with household jobs. Adulthood - shopping, cooking, washing and cleaning.
- Nutrition – if there are any difficulties with eating or taking in calories, describe them, but also explain that early years growth can be difficult as the child must take in more calories than other children. As the young people age and move into adulthood balancing calories and reduced activity can be difficult. The Fontan circulation depends on a good fluid intake so maintaining hydration is very important.

- Development – any developmental delay (normal in a child with half a working heart) diagnosed educational deficit. Include any educational psychology reports.
- Education – What support has been put into school, college or university- copies of Health Care Plans and, where appropriate, copies of Education Health Care plans.
- Work Place – what support has been put in place, have any benefits for reduced working been put in place.
- Mental health. Are there any concerns or treatment for mental health problems? Psychologist or school pastoral care.
- Social life – explain how much inclusion there is or is not.
- Aspirations and how the support of benefits will help them to be reached.
- Talk about inclusion.
- Talk about reaching their full potential.
- Talk about reducing discrimination.

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If you have any further questions, please get in touch with our friendly team by emailing info@lhm.org.uk