

**WRITTEN QUESTION TO THE MINISTER FOR HEALTH AND SOCIAL SERVICES  
BY DEPUTY L.V. FELTHAM OF ST. HELIER CENTRAL  
QUESTION SUBMITTED ON MONDAY 23rd OCTOBER 2023  
ANSWER TO BE TABLED ON MONDAY 30th OCTOBER 2023**

**Question**

“Will the Minister outline what support her Department has in place for the families of children that are diagnosed with chronic health conditions or terminal illnesses?”

**Answer**

In Jersey there are a large number of children who have a range of long-term conditions such as asthma, epilepsy, and diabetes. These children and their families are supported through the HCS general paediatric service, and a range of specialist clinics led by paediatricians and specialist nurses. For the majority of these children, their health condition is controlled, and the aim of the support provided is to minimise the impact of health on a child’s physical, social, and educational development. This is achieved by provision of co-ordinated multidisciplinary care organised through the hospital clinic, including provision of education and training in self-management to the child and the family. Where appropriate, this also includes provision of support in schools and training of teachers in relevant aspects of a child’s medical management, to minimise the impact on school attendance and academic attainment. For those children with a long-term condition requiring tertiary level medical input, there are a range of clinics provided by visiting consultants on island (e.g., in neurology) and there are referral pathways to UK tertiary centres in cases where other expertise is required. The families who need to travel to UK for tertiary care are supported with their travel arrangements including flights and accommodation by the HCS travel service.

Sadly, there are a small number of children who have more serious health problems requiring complex intervention and extensive support including those with a terminal condition who are not expected to live to reach adult life.

For these children, a care pathway was launched in 2016 based on the principles set out by the UK charity ‘Together for Short Lives’ that is considered to reflect best practice in the UK (available here). This pathway is managed jointly by the HCS Paediatric team and Family Nursing and Health Care (FNHC). Up to the end of 2022, there were 58 children managed on this pathway and as of writing, there are currently 27 on the pathway.

Many elements of good practice and themes are taken into account when planning support for the families of these children. Bespoke care plans, often multi-disciplinary in nature, are completed with the child with their family. Assessment of a family’s needs involves ongoing, in-depth gathering, recording, and sharing of information. Regular, clear, and unambiguous communication is key in supporting each family. With families where English is not their first language, interpreter services are provided to facilitate the discussions with healthcare professionals. Community support is provided by nursing and health visiting teams from FNHC and in some cases this is supplemented by support provided from other specific charities. This support includes direct nursing care at home and provision of training and education to children and families to help with ongoing management of the child’s condition. The community nursing team also provide liaison with educational establishments to ensure that there is appropriate support and a classroom health plan in place.

For children on this pathway access to medications has been facilitated, as have access to hospital appointments and investigations, to reduce the burden of illness on the families. In some cases, this includes provision of medication from the hospital pharmacy and delivered to the child and family as part of the FNHC home visits. Acute presentations are given priority at the hospital with defined care plans in place, in anticipation of a child's needs at the time of any predicted deterioration in their condition. In addition, emotional and mental health support is available to families who are struggling, fatigued, or stressed about health conditions of their children. The community care team review sibling wellbeing, in addition to supporting the affected child, and give due consideration to any safeguarding issues that may arise in relation to the care arrangements in place. Where appropriate, additional support may be provided by liaison with the community mental health team.

The impact of living with a long-term condition can also have a significant financial impact on a family, and so this is considered as part of the multidisciplinary team assessment. Where appropriate, families are referred to community and local services in respect of this aspect of care, and in addition are provided information on local charities which may be able to offer additional resources and support to help the family cope with the demands of providing ongoing care.