

**Palliative Care Inquiry**  
**Fact Finding Visit to CHAS Rachel House, Kinross**  
**18 September 2015 10.00am to 12.00pm**

**Attendees**

Rhoda Grant MSP

The visit to CHAS Rachel House had the following agenda:

**10.00-10.30** Meet with Maria Gill, Chief Executive, CHAS and Sue Hogg, Director for Children and Families, CHAS. Overview of services provided and then tour of the facilities.

**10.30-11.00** Meet with CHAS staff including:

Diana Nurse (neo-natal services)

Charge Nurse

Physiotherapist

Activities Coordinator

Senior Support Worker

Chaplain

Nurse

,CHAS “at home” Care Manager

**11.00-12.00** Meet with parents using CHAS Rachel House

Tour of the building

- Prior to 1996 there was no children’s hospice provision in Scotland – nearest was Leeds.
- Rachel House can provide residential support for eight children and their families at one time. Length of stay varies, there is no set pattern. Average around 170 families receiving support from CHAS at one time.
- CHAS provide both hospice support and a home service for children up to young adulthood (21 years old).
- Referrals to the hospice are made via a range of practitioners; social workers, consultants etc. and self-referral by the child’s family.
- Predominately provide care to non-cancer patients.
- Currently there are three Diana Nurses covering Scotland.
- CHAS offers family rooms. This allows for siblings to also be involved in the respite process. It helps with family bonding. The siblings who would also be involved in care can come and relax along with the service user. This makes the whole situation less stressful.
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- Children who receive CHAS services can be described as falling into the following four groups:
  - Life threatening –end stage cancer the largest unmet need. Early involvement is key for this group but harder to achieve as focus is on cure/treatment of condition.

- Chronic conditions – which is likely to result in the individual dying young – cystic fibrosis (less cases now referred) Muscular Dystrophy (an increase in cases referred)
- Progressive/palliative conditions – Edward Syndrome, Batten's Disease.
- Static conditions – unlikely to survive childhood – spinal cord injuries,.

**Meeting with staff issues discussed:**

- Lothian's described as good practice example. They have excellent use of Anticipatory Care Plans (ACPs) and excellent Children's Community Nurses (CCN). This allows for families to record their wishes for end of life choices, including place of death.
- Aberdeen and other areas outside the central belt do not have ACPs and CCNs in place and as such the provision of palliative and end of life care is not as good. This needs to be addressed. Provision needs to be the same all over the country. At present it is a "postcode lottery".
- Lothians provide "CARE24", a 24 hour end of life service. This is used by people who have highlighted in their ACPs that they wish to die at home. This service is run in conjunction with CHAS. NHS provides cover during the day and CHAS provide it at night. Some frustrations expressed that this service is not provided everywhere.
- It is about giving people choices, but to do this the resources need to be identified and provided for.
- Suggestion made that hospitals are getting better at palliative and end of life care. There is however still a fear within hospitals that they have a patient that seems at end of life but then they make a slight recovery and stay for weeks. Having been working on the basis that the patient was at "end of life" stage the hospitals then seem to struggle how to re-start palliative care.
- Definite improvement since Diana Nurses were introduced. There are now regular discharge meetings during which the Diana nurse and specialists discuss palliative care needs
- Diana nurses give parents the opportunity to complete ACPs. They are now present from 20 weeks if a scan shows problems. This allows the family to have ACPs in place at ante-natal stage. Parents can find it easier to discuss emotional issues before the baby is actually born. It allows planning for "memory making" and brings it back into a positive environment. It also enables support to be delivered before crisis point is reached.
- More frequent meetings now take place between specialist nurses and CHAS. They discuss the children who are receiving support from CHAS and they can inform the hospital specialists of their ACPs.
- Doctors need better training and education on palliative care. At present bereavement and end of life training is only one lecture. There is a desire from medical staff to attend specialist palliative and end of life care training but this is not a priority or mandatory course. As such medical staff generally have to attend on their own time.
- Needs to be a better understanding of what palliative care is. General understanding is that it is only end of life care. Coming to a hospice should not be perceived as giving up hope.
- Need to parallel plan both ongoing treatment and palliative care. Palliative care nurses need to be involved sooner. They would rather they were

involved in the anticipation of palliative care being required and then if it isn't they can stand down.

- Trajectory of progression of children's conditions not as recognisable as adult conditions as they may be in and out of hospital, need to recognise when a child's condition is deteriorating.
- Often parents focus on physical wellbeing but CHAS helps them also focus on emotional wellbeing.

### **Meeting with parents issues discussed:**

- Two very different experiences of palliative care and accessing CHAS services.
- The two parents the Committee met with had very different experiences of accessing support. One received no support through their local authority while the other had received support from their local authority since the birth of their child. This included complex care provision.
- Both described how "everything was a fight" to ensure their child received appropriate care and support, even basic provision of nappies for the child when they were in hospital
- Both agreed that CHAS was a lifeline. "CHAS are always there to listen and can usually help as well." "They look after my child as I would"
- "CHAS offers a service with no judgment. This is imperative".
- "CHAS ensure that a child's dignity is maintained and fosters an enabling culture. CHAS is a fun place for my child to come"
- Some concerns raised regarding the support the parents received in hospital regarding learning how medical equipment used by their child operated CHAS has been a vital resource for the parents in providing them with practical support on how to use feeding pumps etc.
- Both parents explained how their child's conditions could fluctuate quite significantly. They could go from being relatively well (in their context) to severely unwell quite quickly. And on the converse they could get back to equilibrium quite quickly as well. They felt this was understood at CHAS but not within a hospital environment. Emphasis was placed on the importance of hospitals recognising these fluctuations so that they could identify when providing palliative and end of life care was appropriate..
- Both believed that CCNs were very helpful but vastly understaffed. They felt that staff needed more training to be able to deal with children with complex needs.
- Need CCNs specifically for children with complex needs.
- Need more Nurse Prescribers. This allows for prescriptions to be written without having to go to the doctor.
- Discrepancy between what care is provided at home and then when they are in hospital. One parent explained that they got 6 out of 7 nights covered by a nurse. However when her child goes into hospital there is no night cover. The parent explained that this resulted in them being isolated in the hospital. The parent called for more consistency in the level of care provided.
- They have a sense that different help comes from different pots of money. This needs to be more consistent across Scotland.
- "CHAS and other associated services MUST be funded"

- Additional needs which are not funded need to be. This included the instance where the parent was able to access funding for a wheelchair but not a specialist car seat. The parent would have to find the £3000 funding for the car seat.
- CHAS has supported the parents in taking the fear away from the situation that they and their child are facing, “CHAS enable you to recognise that everyone is on the same unknown path”. CHAS has supported and encouraged discussion of their child’s Anticipatory Care Plans – what the planned support should be if/when child becomes more unwell. CHAS have also encouraged the parents to keep these plans up to date to reflect changing family circumstances and the child’s health needs.