

Young Lives vs Cancer

Social Care Team

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30 June 2022

To Whom It May Concern,

**Re: Jason Howard Carter
father of Drew Howard Carter (D.O.B 09/05/2018)**

I am aware that Jason is currently liaising with you regarding their personal circumstances and how this is impacting on his work life. I am writing on Jason's behalf to provide further information about these complex family circumstances including how they are impacting on his wellbeing and ability to work, as this can be a difficult topic for parents to talk about themselves.

Jason and his wife jointly care for their children: Drew and Jude (aged 4 and 6). Drew has been extremely unwell since May 2022, and it has been necessary for Jason to take leave from work since this time due to these unforeseen health needs.

Young Lives vs Cancer became involved with this family as a result of Drew being diagnosed with Acute Lymphoblastic Leukaemia on 29/05/2022. Our role is to offer practical and emotional support to families where a child has been diagnosed with a form of cancer. I am working with the family to try to help manage the impact of Drew's illness and treatment which will be ongoing for a least the next 3 years. Drew's condition and treatment needs have greatly altered 'normal' day to day life for the whole family.

Drew is being treated with chemotherapy. His treatment itself has to be extremely intensive which results in a significant increase in both the practical and the emotional care that Jason needs to provide. Drew requires help and support with hospital appointments, unpleasant procedures, careful administration and monitoring of his drugs, and constant vigilance regarding his health and possible of infections. Drew is immunosuppressed and at risk of developing infections which are potentially life threatening – urgent medical advice must be sought if there are changes in temperature and unplanned hospital admissions may be needed for intravenous antibiotics. Drew needs his parents to provide constant supervision while undergoing treatment to monitor his condition, to provide essential care, and to support him emotionally. In fact, the demands made on Jason by Drew's condition are total while they are undergoing treatment and this will continue to be the case for a considerable time after treatment is complete as the effects of treatment (both physical and emotional) will be cumulative.

When Drew is visiting hospital, whether as a day case patient or an inpatient, it is necessary for his parents to be at Birmingham Children's Hospital with him to offer emotional support to him, in addition to supporting each other in taking in all of the information that is being given to them about his condition and treatment needs. Life on the hospital wards is exhausting for any parent; alongside the emotional impact that Drew's current condition has on their parents, they also face disturbed sleep in shared bays, financial strain, and social isolation. We encourage all parents to be actively involved

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with their child's medical care as research suggests that this can provide improved treatment outcomes. It is the policy and practice of the ward that parents undertake every aspect of their child's care during inpatient stays and outpatient appointments. It is extremely important for Drew's emotional and physical wellbeing for his parents to be at the hospital with them as much as possible. Drew's care needs remain very high when they are at home and, as much as possible, Drew's parents try to manage his care jointly.

Jason is a dedicated parent whose focus is to ensure that family life is settled for their two children. Drew's sibling is concerned about their little brother and it can be a very unsettling time emotionally for siblings. Drew's medical team will try to allow them to have as much 'normal' time out of hospital as they possibly can, but this will depend on their treatment protocol and how well he is. We hope that he will be able to spend as much time as possible at home when he feels well enough, to ensure that he continues to have 'normal' social interactions and experiences.

Most of the parents we work with are understandably extremely anxious about their child's treatment. Watching their child go through so much is traumatic. Jason is seeing Drew suffering from sickness, pain, exhaustion and dramatic body changes in addition to numerous invasive procedures and investigation. The treatment of a child with cancer significantly affects the whole family, not just the child receiving treatment.

Jason has talked with me about his loyalty to your organisation and whether it would be possible for him to manage working life alongside the daily impact of his son's life-threatening illness. I understand that your organisation has been extremely supportive to date and I trust that you will support Jason in whatever way you are able if they need to seek more flexibility in their work arrangements in the future.

I hope this letter will provide you with a greater understanding of Drew's need for care and attention, and that you will continue to view Jason's situation sympathetically.

If you require any clarification or further information, please do not hesitate to contact me.

Yours faithfully,

Rhona Jackson

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