Structure and organisation of a paediatric palliative care letter.

Richard Hain January 2018

Generally speaking, the readers of most clinical letters will read the first page and only go on to the rest if they see something that alerts them to the fact that they should. In many specialties that often doesn’t matter, because a clinical letter can be just a record of what the hospital team has decided to do. But in palliative care we depend on working with colleagues on different sites and from different backgrounds, and so it is particularly important that in our letters we make it as easy as possible for the reader to assimilate quickly and easily what is important.

The structure of a palliative care letter should be something along the following lines:**1. GP action.**

This has to go at the top, so that busy GP will immediately know they need to take note of the content of the letter.**2. Name and address of patient.**

Use NHS number, please, because our patients are often cared for by several different hospitals/surgeries and patient numbers will differ.

**3. introductory paragraph.**

Should not reiterate information the reader already has. Should be just enough to locate the advice you are about to give in the context of the specific patient. So here, you could say something like “ As you know, this young man has relapsed, widely metastatic neuroblastoma for which there is unfortunately no longer any prospect of cure. He is currently in Ty Hafan Children’s Hospice for end of life care. We reviewed him at Ty Hafan today, 2 January 2018.”

**4. List of symptom problems.**

In this section, it is important to focus on symptoms, rather than general paediatric or oncology problems. Of course, symptoms may be connected to those problems, and so may need to be mentioned, but the focus of a palliaitive care letter should be on the symptoms rather than their cause. Common poblems would be physical problems such as pain, psychological ones such as anxiety and existential ones such as patient and family preferences for location of care at the end of life. In this section, you should list all of the problems you have identified in your discussion with the patient and family, and for each one expand on the cause for it, and if possible what interventions seem to help.Note the symptom list should not be limited to ‘physical’ symptoms alone.

**5. Plan.**

This should be a list of specific interventions (eg ‘Increase breakthrough oramorph to 3mg as needed’ or ‘No change to Midazolam dose’ – if that’s relevant – or ‘We will contact Play Therapist’.) Each point on the list should ideally occupy less than one line.

Tha plan should flow clearly and intuitively from the list of symptoms you have set out. So if you have talked about pain, the plan should set out exactly what you are plannig tto do about the pain.

The plan should also include your ‘plan B’. “If this doesn’t work [in such and such a time period], then we will try that”

The plan should finish with the plans you have made to review the patient.

**6. Diagnosis and medication lists**

These have to go at the end, because they are typically long in palliative care patients and can occupy the whole of the first page (meaning the reader won’t always read to the important bit, which is the plan).

**7. Copy list**

The copy list is effectively a statement of who is part of the virtual team caring for the child. It should include:

* The GP (by convention we usually address the letter to the GP, although it is also reasonable to address it to the referring consultant)
* The consultant who referred the patient to palliative care
* The lead consultant (if different from above)
* The local palliative care doc
* The relevant PPCNS or POONS
* Team leader and/or consultant at Ty Hafan or other hospice if they are involved.

We don’t usually send copies of palliative care letters to the family, because the information can be particularly traumatic and it can be difficult to express it sensitively enough in writing. But there are certainly times when we should. Under those cirumstances, the letter should be written carefully, and primarily with the feelings of the family in mind. It should always be written as though the family were the primary recipients, even if they are in fact only getting a copy of a letter addressed to someone else.