

Your Right to Receive Copy Letters

As one of the NHS Plan July 2000 was a drive for greater openness in dealings between the NHS and its patients and a commitment that patients should be able to receive copies of clinicians' letters about them as a right. This commitment is now required to be fulfilled. As a general rule and, where patients agree, letters written by one health professional to another about a patient should be copied to the patient or, where appropriate, parent or legal guardian. The general principle is that all letters that help to improve a patient's understanding of their health and the care they are receiving should be copied to them as of right.

A letter includes communications between different health professionals. Different types of letters include:

- Letters or forms of referral (including hard written two-week wait referral forms) from primary care health professionals to other NHS services
- Letters from NHS professionals to other agencies (such as social services or housing, employers or insurance companies)
- Letters to primary care from hospital consultants or other healthcare professionals following discharge or following outpatient consultation or episode of treatment

There may be reasons why the general policy of copying letters to patients should not be followed and one reason may be that the patient does not want to receive a copy. If this is so, the patient's wishes will be respected.

You should be asked for your consent to receiving a copy of the letter and making and sending copies. There is a suggestion in the Good Practice guidelines that the circumstances of each letter may be different and that it would be good practice to obtain patient consent for a receipt of a copy of each letter.

Over the next years teams are going to have work through the issues, practical difficulties and even conflicts, for example:

- Medical administration and information handling will be under close scrutiny. It needs to be pointed out that the Government has not provided any extra funds to fulfil this commitment. This will present practical difficulties. For example, Great Ormond Street Hospital estimates that when fully implemented it anticipates copying letters to more than 75,000 families per year.
- If consent needs to be given each time to receiving a copy of a letter the administrative burden is increased.
- It needs to be clear who is responsible for a child. Much needs to be clarified for children in care, separated families etc. This will likely take time.
- The guidance leaves the responsibility for obtaining and recording consent and for ensuring that copies of letters are appropriately provided to the correct recipient with the person who writes the letter.
- Young people over 16 should themselves be offered copies of letters. They may choose to show letters to their parents or withhold it. Professionals will need to actively check out a young person's level of understanding before offering letters. This too will take time. Some CLDF parents may have difficulty with this given that they have been dealing with their child's illness since birth in many cases.
- There is a responsibility placed on the family and the patient with this commitment. It would be helpful if families have discussed this amongst themselves outside of the clinic situation.

This subject has been a topic covered at the CLDF Question Time at the annual conference and the overwhelming view of the parents present is that they would like copies of letters. We would like to hear from parents as to their views on this subject and possibly, in an ideal world, what information they would like to receive.

We would like to point out that this commitment has enormous implications for the units treating your child. It will take time for them to develop systems

and sort out the problems which will inevitably occur. The teams ask for your patience whilst they do so.

If you would like to read further on this subject go to <http://www.dh.gov.uk/Home/Is/en>. If you type in copying patient letters into the search part of the site then you will find a list of references.

Support Objectives

CLDF has a range of plans in terms of family and patient support. There is so much to be done and with limited resources the Foundation has to make decisions as to what it can and, just as importantly, cannot do. CLDF has a long term goal of building its support services. In the meantime, the trustees have agreed a phased programme to start the process.

This year the trustees aim for CLDF to achieve the following:

- To finance and once raised, to employ a second family support officer
- To hold a memorial service in June 2004
- To complete and launch parent leaflet and patient series of information in the "Taking your liver disease into adulthood programme"
- To undertake the following activities leading to the development of understanding and programmes for support:
 - To develop and implement a Young Person's information Pack
 - To provide evening support once a week to young people
 - To develop a web based information service for young people linked to the CLDF website
 - To undertake research into young people's needs
 - To develop relevant from the research for input into the 2005 - 2006 business plan