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Personal patient-held 'health books' – should everyone have one?

In this age of electronic media, here is an idea for South Sudan's health services. Massimo Serventi, a doctor with wide African experience and presently working in Darfur, suggests that everyone, especially children, should have and *keep* their **own personal paper 'health book'** – and keep it throughout life. The main aim being to improve the diagnostic orientation of health professionals.

Dr Serventi first introduced these books when he was working in a public hospital in Tanzania. He asked every patient to buy an ordinary exercise book, available in the shops at low cost. In this book, the doctor (or other health professional) had to write:

- date
- short history of the current illness (e.g. fever for 3 days, cough for 1 week...)
- major signs and symptoms
- suspected diagnosis
- treatment (including non-pharmacological recommendations)
- signature (easily readable)
- rubber stamp (if possible).

Any laboratory results were enclosed *in* the book which the patient (or parent) kept.

These books functioned well for several reasons:

1. Medical contacts were in chronological order. As prescribers, we know that many hospital forms are not easy to read and are often mis-filed; if there are many it become difficult to trace the chronological progress of the disease. And this is important especially in cases of chronic illness, such as diabetes, asthma or hypertension.
2. Doctors were 'obliged' to write clearly *all* important information; they knew that other colleagues would see the book in the future.
3. They helped the doctor make a diagnosis. The doctor could *see* in one place all the previous medical contacts. Many times the information on previous pages gave a clue to the present ill-health problem. Example*:* Dr Serventi says, *"Suppose I read in the book that a child had several episodes of otitis in the first year of age, recurrent abscesses of the skin, oral thrush and a poor growth.....then I would consider investigating her HIV status."*

If in-patient files were missing the book was used to follow the progress of admitted patients.

Dr Serventi remembers that the 'natural' opponents to patient-held records were hospital administrators who wanted the record of medical contacts to *remain* in the hospital, and researchers who needed to analyse records. Although Dr Serventi agrees that duplicate records can, and perhaps should, be kept by the health facilities, he believes that patient-held records are *more important* because:

1. Files left in the hospitals are easily lost and privacy is not guaranteed.
2. A file left in the hospital does not allow a second doctor to orient him/herself. In case of deterioration of the health condition (maybe in the middle of the night) the patient should be able to *show* to a second doctor how he or she was previously treated. Or, if travelling somewhere else, the patient can show his/her past health history to other health staff and request that it is properly filled in. All the health professionals that the patient sees whether in a private or public clinic/hospital, should write on the same book.

A health book like this encourages us to *write down* what we see and feel openly (even if we put a question mark to show that we have not yet come to a clear conclusion). Dr Serventi says, *"No-one should leave a consultation room without all the doctor's findings and conclusions written in her/his health book."* He adds, *"All patients have the right to have their books properly filled and to keep them for ever".*

"A car service report is kept in the car....and not in the garage."

Examples of other patient-held paper health records

The most well-known is the child growth/health chart promoted by David Morley and still widely used although this only covers the individual until about the age of five years (www.talcuk.org/accessories/child-health-charts.htm). According to the email forum HIFA2015 (see www.HIFA2010.org) patient-held paper records are also being used in Nigeria, Malawi, Indonesia and South Africa. And below there is an example from UK.

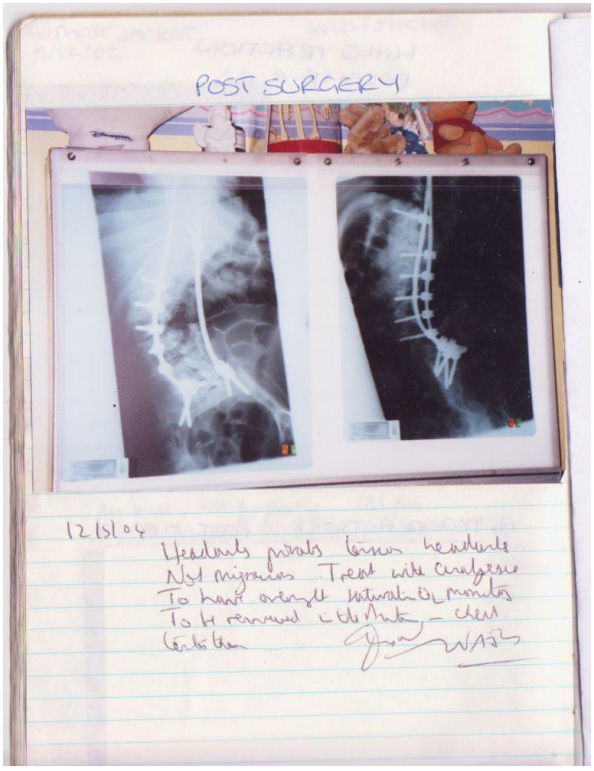
Dr Serventi says, *"Whatever is used (e.g. a card or exercise book) there must be there space enough for the health professional to write down all information obtained in that consultation (i.e. the findings, diagnosis, lab results and treatment)".* He emphasises that a health book should not 'belong' to a certain hospital, NGO or institution. It should not be used only to record special diseases.

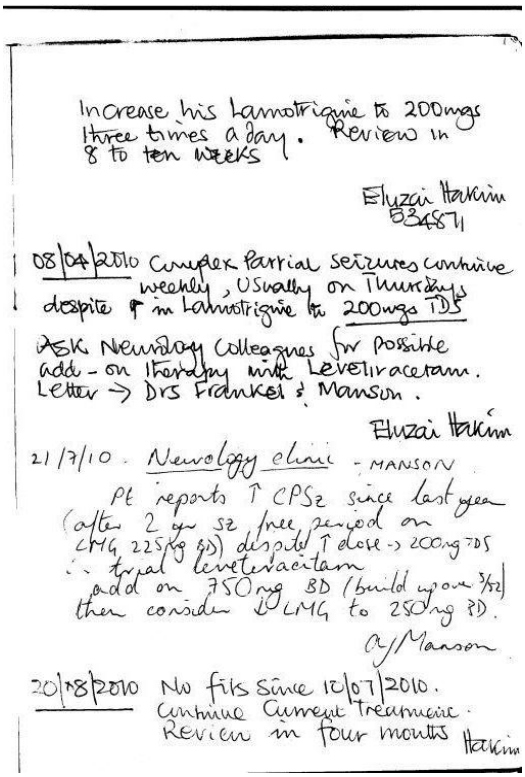
Example of a health book from UK

Below are two pages from the 'health book' of a male patient (DN) living in UK who was born in May 1989. DN was diagnosed with congenital muscular dystrophy, complicated by scoliosis and later on developed complex partial seizures. He needed to be seen in various clinics by different specialists who managed his physical disabilities and epilepsy. The complexity of DN's condition necessitated a record of each visit to enable parental understanding of DN's treatment and follow up arrangements.

DN's mother says, *"I have held this exercise book as a complete record of hospital appointments, investigations, surgical procedures and medication from my son's birth to the present day. At each appointment a brief note of any procedure or advice was noted for future reference. The book has been an invaluable source of information for me, and for all the healthcare professionals who have been involved up until now - and will be for any who may be involved in the future".*

Two pages from DN's health book *(published with permission of his mother)*





Do you agree with Dr Serventi that what is *wrong* and *does not* help are those papers (from hospital or private/public clinics) where the prescriber writes, "erytromycine 5mlX4X5days, paracetamole5mlPRN" and nothing else – with *no* other indication of the disease treated, the complaints, the symptoms or the diagnosis?

Note: a doctor in this article includes any health professional who diagnoses, treats and counsels patients.