



TEACHING CHILDREN WITH MEDICAL NEEDS

HOME AND HOSPITAL EDUCATION: A GUIDE TO INTERNATIONAL INNOVATIVE PRACTICES



The LeHo project has been funded with support from the European Commission.

The content of this document reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of theinformation contained therein. Project number: 543184-LLP-1-2013-1-IT-KA3-KA3NW

This document is licensed under a Creative Commons Attribution 4.0 International license except where otherwise noted.





Table of Contents

Table of Contents	2
Introduction	4
Some background information	6
The international dimension of education for children with medical needs	
UNESCO children's rights on education for children with medical needsneeds	
HHE: Terminology	
Possible formats of education for children with medical needs	7
European countries and education for children with medical needs	
Legal aspects	
Organisational aspects	
Some cases of HHE legislation and organisation in Europe	
A comparison between children with and without medical needs	
Successful learning and Key Educational Factors (KEFs)	19
Key Educational Factors	
A. Relationships	
B. Making sense and constructing knowledge	
C. Assuming roles	
D. Metacognition	
E. Individualities	
F. Inter-institutional communication	21
The LeHo forum groups on five KEFs	
Global observations within Focus Group1 (FG1)	22
Summary of the most important observations for each KEF	23
The influence of the learner's medical condition on learning, in terms of the KEFs	24
Information for a teacher of a learner with a medical condition	
Supporting children aged 2 – 6 with medical needs	
Supporting pupils aged 7 – 11 with medical needs	
Supporting students aged 12 – 18 with medical needs	
Profile of an HHE teacher	
Some additional lessons learned from the Forum Group discussions in the LeHo project	35
ICT and the education of children with and without medical needs	37
The potential for ICT in education	
The media debate	
Is this debate still valid for today's learners?	
The potential of ICT for the education of children with medical needs	
How can ICT be used effectively?	
ICT for children with medical needs: Lessons from the LeHo toolkit and training actions	43
ICT support for teaching	43
Materials and tools for teachers	43





Materials and tools for pupils and students	44
ICT support or communication	45
ICT support for management of the learning/teaching process	
Use of a Virtual Learning Environment (VLE)	47
Real-time distance education	48
Collaboration between HHE entities	50
Money, money, money makes the world go round: Funding support for HHE	50
Conclusions	51
References	52

Cover picture: (Image: Wesly Fryer. Shared under a Creative Commons CC BY-NC 2.0 licence) modified by LeHo.





Introduction

This Home and Hospital Education (HHE) Guide to international innovative practices is the product of joint efforts within the European LeHo project (Learning at Home and in the Hospital), funded by the European Commission within the framework of its Lifelong Learning Programme. The project aims to outline key factors in the education of pupils and students with medical needs, highlighting good practices dedicated to their education during their stay in hospital and their aftercare (at rehabilitation centres and at home). It explores ICT (information and communication technology)-based solutions for problems that arise with respect to this education, and provides hospital teachers and those who provide home tuition with information and tools to support them in their task. More extensive information about this project can be found at: http://www.lehoproject.eu/.

This HHE Guide can be used alongside other LeHo products, especially the LeHo Toolkit and the other materials that are referred to in this Guide. There is some duplication of the information contained in these materials but this Guide also provides teachers with pathways that lead to quality education for pupils and students with medical needs. Furthermore this Guide is in the format of an e-book, whereas the other materials in the LeHo project may be multimedia.

For whom is this Guide intended?

The Guide can be beneficial for:

- Teachers who have no, or only limited, experience with children and students with medical needs
- Teachers who already have experience of teaching this group of learners

How to use this Guide?

The Guide can be used as a reflection and study book for personal use, but we suggest that it is best used with groups of teachers (e.g., colleagues within the same school, but also groups of teachers from different educational settings) to work through together.

Terms that are used in the Guide are normally explained in the text. An extended glossary of terms related to HHE and ICT is part of the LeHo website and can be consulted here: http://www.lehoproject.eu/en/glossary.

To help start your reflection and discussions with colleagues, two support aids have been added to the text of the Guide:

- Balloons in the right-hand margin provide indications to the content of the adjacent paragraphs
- Boxes with questions and suggestions act as "advance organizers" (a term introduced by Ausubel and defined by Mayer as "information that is presented prior to learning and that can be used by the learner to organize and interpret new incoming information")¹.

It is hoped that you will be prepared to share any new insights arising from these discussions, or from your own personal reflections, with other teachers throughout Europe, along with any experiences of innovative practices that you have tried (and which have hopefully been successful). The LeHo toolkit





(http://www.lehoproject.eu/en/toolkit/) has a dedicated section for you to do so: simply use the "Add Entry" tab in the menu.

References for further reading provided in the text can be found at the end of the Guide. In the Table of Illustrations, accreditation is provided for any copyright images, along with a reference to the page where the illustration is used.

Aims of this Guide

After working through the Guide, you should:

- 1. Have obtained a better understanding of the complexity of education for children with a medical condition
- 2. Have gained new insights that may lead you to improve the quality of your work and/or additional tools that support your practices in HHE
- 3. Have fostered stimulating relationships with colleagues in the (hospital or/and mainstream) schools your pupils attend.





Some background information

In this section you will become familiar with the international conventions on which national legislations are based and with the various formats that education of pupils and students with a medical condition can take.

Before you start reading, please consider the following questions and what your answers would be:

- 1. Is it necessary to provide a specific type of education for pupils and students with a medical condition? And if so, why?
- 2. In which aspects should education for pupils and students with a medical condition be different from conventional education?
- 3. For teachers with experience in this type of education; which aspects of the education you provide are clearly successful/beneficial, and which aspects should be changed/optimised?

The international dimension of education for children with medical needs

UNESCO children's rights on education for children with medical needs

The UNESCO Universal Declaration of Human Rights (1948)² describes the right to education for everyone as a fundamental right (art. 26). The goal of a human rights-based approach to education is simple: to assure every child a quality education that respects and promotes her or his right to dignity and optimum development.

This fundamental right has since then been affirmed in numerous global human rights treaties, including the UNESCO Convention Against Discrimination of 1960, the Convention on the Rights of the Child of 1989 and the UNESCO Salamanca Resolution of 1994, which explicitly adds the principle of inclusion in education policies. Most UNESCO member states ratified the Declaration and Conventions, thus embedding the right of children to education into their own legislation.

Further explications of these rights can be found in numerous publications, e.g., "A Human Rights-Based Approach to

The right to education: Article 26 of the Universal Declaration of Human Rights

- Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
- 2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of
- 3. Parents have a prior right to choose the kind of education that shall be given to their children.





Education for All".3

Furthermore, article 14 of the European Union Charter of Fundamental Rights, dating from 2000, confirms the right of children to education. It became a legally binding issue for all member states of the Union in the Treaty of Lisbon in December 2009.

However, the explicit right to education for children and young people with medical needs is considered in these conventions and treaties, nor are the rights to education of disabled people. In practice, however, ratification has led to adaptations in the national systems, laws and regulations that provide more or less comprehensive measures for different educational settings during illness and medical treatment that can take place in the hospital, at home or in other places.

HHE: Terminology

The HHE acronym has been introduced by the LeHo project as the abbreviation for the term "Hospital and Home education". The term and the acronym refer to the activities related to the broad world of education for children or young people with medical needs. These take place in hospital

Hospital and Home Education

(hospital school), in hospital-related locations, or at home (sometimes also referred to as home tuition).

Possible formats of education for children with medical needs

Due to medical progress there has been an increase in the number of children and young people with medical conditions in most countries. The extension and improvement of services for their education is therefore a logical requirement.

Education is possible throughout all the phases of hospitalization: from diagnosis, treatment and aftercare, i.e. in the hospital, to rehabilitation in hospitals and centres, at home and even in the mainstream schools (the school that the child usually attends when being not ill). Where almost all countries have traditionally developed structures for education in the hospital, formats for this education have been also created for home tuition. With the increasing importance of outpatient clinics for the medical care of pupils and students with medical conditions, these children are more often able to continue to attend their regular schools.

Hospital school



(Image: <u>Wesly Fryer</u>. Shared under a Creative Commons <u>CC BY-NC 2.0</u> licence)

A hospital school is a school located in the hospital environment, generally in a specialist children's hospital, where the school provides instruction to primary and secondary grade levels. These schools provide education to children during periods of hospitalisation or rehabilitation to keep them up to date with their peers in their mainstream school. The schools are most often accredited (and run by the local public school system), funded by the state, and teach the same curriculum as the mainstream schools. Enrolment numbers are usually low when compared to traditional schools and teachers must provide instruction across many grade levels.





Most countries in Europe have hospital schools, at least in their larger hospitals. However, as hospital schools operate under the local regulations and the laws of the country or region in which they are situated, a variety of settings can be encountered:

- In some hospital schools, children with medical conditions can attend classes following the hospital school's own curriculum (taking into account the level and kind of education the child normally follows in their mainstream school). The advantages of this system for teachers are that they can use familiar handbooks and that teaching and learning materials will be available that can be adapted to switch between classical and more individual teaching. It offers teachers the flexibly to adapt their teaching/learning support in line with the treatment regimens. Not all subjects will/can be covered by this type of education: Often the child's concentration and effort are limited by the illness and the treatment, and some practical and technical subjects often require specific equipment that is not available in hospital schools. For this reason, subjects taught in the hospital school often cover only the main core subjects.
- Other hospital schools try to match, as far as possible, the child's mainstream school pedagogical system. For this approach, they must contact the mainstream school of each child to obtain background information and to obtain the necessary teaching and learning materials, and they should follow the mainstream school's didactical approach. This can take some time and not all mainstream schools are willing and able to respond quickly and comprehensively to the request of the hospital schoolteacher. However, secondary school students will often need such an approach, as their curriculum will contain more elective subjects than elementary school pupils. To help with this, the Hospital Organisation of Pedagogues in Europe (HOPE, http://www.hospitalteachers.eu/) recommends that ill children remain enrolled in their mainstream school during their stay in hospital. Continuity of education and a smooth return to the
- Finally, in some hospital schools, teachers act as tutors that support
 pupils and students who are working through learning packages
 (written materials and/or e-learning) provided by educational
 establishments.

mainstream school after treatment can be supported in this way.

...or providing tuition instead.

Home education / home tuition

In the context of HHE, the terms home education and home tuition indicate the teaching of pupils and students with medical conditions at home or at another venue other than a hospital (e.g. during home therapy or in a phase of aftercare) to allow them to carry on with their studies.

Teaching at home

Teaching at home by a teacher will normally be carried out on an individual basis. The teacher may be one of the mainstream school staff members able to teach the child at home (often for a limited number of subjects and for a few hours per week), or someone specially appointed by a local or regional educational authority to fulfil this task on a regular basis for

A limited number of hours of face to face teaching







(Image:©http://www.ond.vlaanderen.be/ toah/professional/)

a number of children with medical needs. As it is the case in hospital schools, teaching at home will be limited to the core subjects or/and subjects that are difficult for the ill child to grasp using self-directed study.

The limited number of teaching hours that can be offered to each child with a medical condition has created the need for additional tuition support by assistant teachers, parents and volunteers. In some countries this support is organised by the local authority (especially for the teaching assistants), but often it happens in an ad-hoc fashion using unpaid volunteers.

Asynchronous teaching and learning at home

For distance education there is a great deal of material available to enable asynchronous teaching and learning at home. These materials vary from complete packages that can lead to certificates and diplomas at various educational levels, to specific training packages aimed at providing a deeper understanding of subject items to support the acquisition of skills through

Distance learning with coaching and tuition

exercises and self-evaluation. Originally these materials were produced in written form only and these were eventually complemented with radio and television transmissions. Developments in ICT,



(Image: © Bednet vzw (http://www.bednet.be/))

however, have enabled completely new formats to make these packages more interactive and tailored to the individual learner. Commercial companies as well as non-profit organisations have responded to this new demand by developing materials that can be used by everyone, including pupils with medical needs. To make these packages commercially viable often the materials do not entirely match the education programmes that are taught in individual mainstream schools but nevertheless, they can provide an interesting addition for pupils who are confronted with a medical condition. Today these materials are often available in

a digital format with embedded tuition, as well as the ability to contact tutors asynchronously (and sometimes even synchronously) to pose questions and ask for help. One drawback for the commercial packages is that they can be relatively expensive as they are not an integral part of the educational system. Consequently they are not subsidised by the government, unlike hospital schools and home teaching.

Mainstream school

Most of these schools are accredited by an education authority at local, regional or national level, and consequently operate within the organisational and curriculum regulations that are set by law or decree. In the past, the majority of these mainstream schools almost only catered for "normal" students; students with disabilities were oriented towards "special education" schools.





Inclusive education formats

Over the last decades the situation changed and there was a shift from special education settings towards education with support in mainstream settings. In a number of European countries this is often referred to as "inclusive education", although the term "integrated education" might be more appropriate, as those who work in special schools regard their work as the ultimate in true inclusion. Inclusive

Attending classes in mainstream school, but with special facilities and additional support

education is a setting in which a child's needs are almost completely met to their benefit and to that of others. This may be experienced anywhere on a continuum of provision and be of a temporary or permanent nature. Inclusion is a state of being, not place. In more recent years, medical advances have



(Image: https://buroverschillig.wordpress.com/vn-verdragart-24/)

resulted in greater survival rates for those with more complex and enduring medical conditions. As more children survive for longer with new and more complex needs, there has been a greater need for specialist placements and multi-disciplinary education and care. Students with disabilities receive extra support through additional didactical activities, adaptations in the curriculum and the provision of devices that help minimise the effects of their disabilities. publications and initiatives that deal with education, inclusive however, have overlooked learners with medical conditions.

This could be because these students are considered to be conventional learners as they are able to attend their mainstream schools normally when they are not ill. However, in considering these students as standard learners, there is the risk that many teachers do not take account of changes in the pupil's attitude towards learning, including their potential changes in motivation for learning, their concentration capabilities and the influence of the illness on their social relationships with their healthy peers. These changes accumulate during the period of illness, but are not reversed immediately when they return to their mainstream school. Furthermore, chronic illnesses have also not been considered in which periods of hospitalisation and subsequent absences from the mainstream school class vary in length and duration, with alternating periods of absence and presence in the mainstream school. Sometimes the changes in attitude are not only seen in the behaviour of the student with a medical condition. When they return to class the medical condition is often no longer apparent and classmates sometimes have difficulty in accepting that this "healthy" child still needs a special approach and attention from the teacher (e.g., is allowed to follow a limited number of lessons, take tests at different times, is not obliged to participate in certain activities, etc.).

Some of the measures used for children with disabilities in an inclusive classroom environment can certainly be applicable for children with medical needs. There are numerous publications dealing with this issue and one example is the UNESCO publication, "Understanding and Responding to Children's Needs in Inclusive Classrooms. A Guide for Teachers".⁴





Mainstream school in hospital or at home: Real-time distance education

An additional way for pupils and students with medical conditions to attend classes in their

mainstream school while they are in hospital or at home is to make use of the internet and use videoconferencing equipment and software. There are many options available,



(Image: © Bednet vzw (http://www.bednet.be/))

ranging from consumer

Attending classes in mainstream school, through videoconferencing and special software

products (e.g., Microsoft's MSN, Apple's FaceTime, Skype, etc.) to dedicated systems (e.g., <u>Bednet</u>). Whether access to the class allows full coverage of all didactical and learning activities or only a small set (e.g. communication with teacher or peers) is dependant of the sophistication of the product used. Furthermore, the medical condition of the learner and the practical requirements of the treatment versus the timing of classes, as well as certain aspects of subjects (e.g. practical lessons) will also limit

the use of this type of technology.

European countries and education for children with medical needs⁵

Legal aspects

Over the past 30 years, all the European nations have created a legal basis for the provision of

education during illness. Often laws at a county or national level will describe the tasks, resources and special competences of a hospital school and the rules for home tuition, sometimes on the basis of a constitutional law. In Belgium, Spain, Italy, the UK and in most Federal States of Germany there is specific school legislation and rules for the education of children and adults with medical conditions.

There is a large diversity between and within European countries; responsibilities shared at various levels and by various authorities...

Different laws cover specific themes e.g. hospital education, home tuition, or to provide special provision in mainstream schools by changing some of the legal standards (e.g. more time allowed for tests and examinations due to the effects of a medical condition). Some national or regional laws define the right to receive and the duty to provide hospital education. They may define limits such as the maximum and minimum number of lessons that can be granted. They may describe the special competence of a hospital school e.g. the right to draw up school reports in special cases instead of the mainstream school. As legislation is shared between the national and regional levels (and eventually at a local level), responsibilities for hospital school education and home tuition services will also be shared between the ministry of education and the regional authorities.

In addition to the educational authorities, the ministry of health and other health institutions may also have an influence on some aspects of hospital school education by setting a framework that also affects the educational activities. These institutions or the hospital management makes decisions





about the availability of teaching rooms, and the services and technical infrastructure required in their buildings. Finally, there are also special hygiene implications and security aspects that need to be considered, for example in teaching in forensic psychiatric wards/school, which will also affect the education offered.

For the most part, relationships between educational services and health services have no fixed guidelines and are negotiated on an individual basis.

Not surprisingly, the use of ICT is governed by a combination of national authorities, such as the ministry of education, and the local authorities. Hospital schools also have to follow the recommendations for ICT use that are set by these authorities. However, the special situation in which hospital schools operate creates certain difficulties. For example, organising internet access for their pupils and

students may conflict with the school's own internet safety and data protection rules. Also, the small student numbers in hospital school classrooms can affect the possibilities and potential of ICT-based group work in class. Technical and setup problems, but also daily management and lack of resources are also more difficult to cope with in hospital schools than in mainstream schools as a consequence of operating on a smaller scale.

Organisational aspects

In all countries, education for pupils and students with medical conditions is an interdisciplinary activity involving teachers, doctors, nurses and therapists, where possible in collaboration with parents. Usually the teachers give the lessons, but they need information about the

An interdisciplinary approach

patient's ability to take part in the learning process and the medical treatments. Teachers often deliver valuable feedback about the patient's educational achievements in interdisciplinary meetings. Some countries have a tradition of using volunteers to give the lessons. In other countries nurses are trained to communicate and deal with the mainstream schools.

To support the children with medical conditions in adapted educational settings and to enable communication between all those involved in this process, some countries, such as Belgium and the Netherlands, have set up counselling services for pupils, parents, the mainstream school and the school administration. However, this is not the case in all European countries and hospital schools form the minority of school types and as such they are often overlooked.

The specific nature of education for pupils and students with medical needs receives scant attention in the initial teacher training courses and in subsequent continuous professional development. Hence, associations for hospital teachers such as the Hospital Organisation of Pedagogues in Europe

Hospital teachers and HOPE

(HOPE), that supports the development of hospital education and home tuition (http://www.hospitalteachers.eu/), are very important. There is an urgent need for a similar international platform for other educational settings. At best, there is an option at the country level such as in the Netherlands, UK and Belgium.

ICT-use has gradually become the norm in education at all levels and in all countries worldwide over the last two decades. Computer- or web-based training, blended learning, mobile learning, educational games, virtual classrooms, video conferencing, social media, discussion forums, communities of

Investigating ICT for HHE





practice, simulations, wikis and more have been welcomed by schools, distance education and professional development. The assumption that these teaching and learning environments and tools are also beneficial for the education of pupils and students with medical condition has been one of the starting points of the LeHo project. It is believed that the well-aimed use of ICT not only is helpful to avoid falling behind in education, but can also help to reduce specific problems in the context of illness, such as social isolation. There is, however, still quite a large knowledge gap about how pupils and students with medical conditions profit from different, high quality ICT applications that could meet their educational needs during their illness. A proper evaluation on how teaching with these tools can avoid any unwanted side effects, both psychologically and educationally, is urgently needed.

Although ICT has large potential for increasing the quality of HHE, it should be used with some caution. Confidential information should be carefully handled and privacy issues respected. Many ill children experience psychological stress as their self-esteem is affected by their illness and their peers can observe these physical changes.

Some cases of HHE legislation and organisation in Europe

More detailed information can be found in the LeHo report, "Institutional environments of HHE in Europe". This report is the result of a larger field analysis on the legislation and organisation of HHE in a number of European countries, including: the United Kingdom, Germany (Bavaria and North Rhine Westphalia), Belgium (Flanders), Italy, Poland and Greece.

Looking back at your answers to the questions at the beginning of this section:

- 1. Have you learned anything new about legislation and the organisation of HHE?
- 2. Select the three most useful items of information with respect to your own situation and discuss your choice and check your selections (and reasons) with colleagues.





A comparison between children with and without medical needs

Should education be different for children with medical needs compared to those without? You may wish to consider the severity and longevity of the need. Is it temporary, chronic or progressive? A graphical representation of the factors and people involved in both scenarios might help to explain this further. The figures below place the focus on the child, but it is also possible to place the teacher at the centre as the focal point.

- 1. When making your comparisons, ask yourself (and discuss with your colleagues) the following questions for each setting:
- 2. As a teacher, whom should I contact?
- 3. Are all those involved equally important? If not, who are the most important ones for me?
- 4. What exactly should I ask them / discuss with them / communicate to them about my educational interactions with the child?

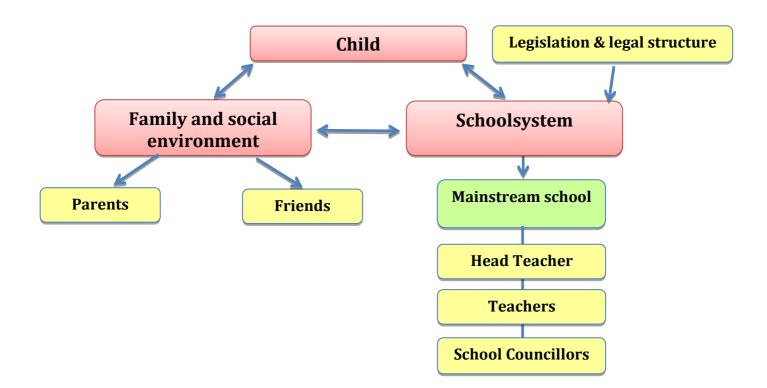


Figure 1. Those involved in the education of children without medical needs

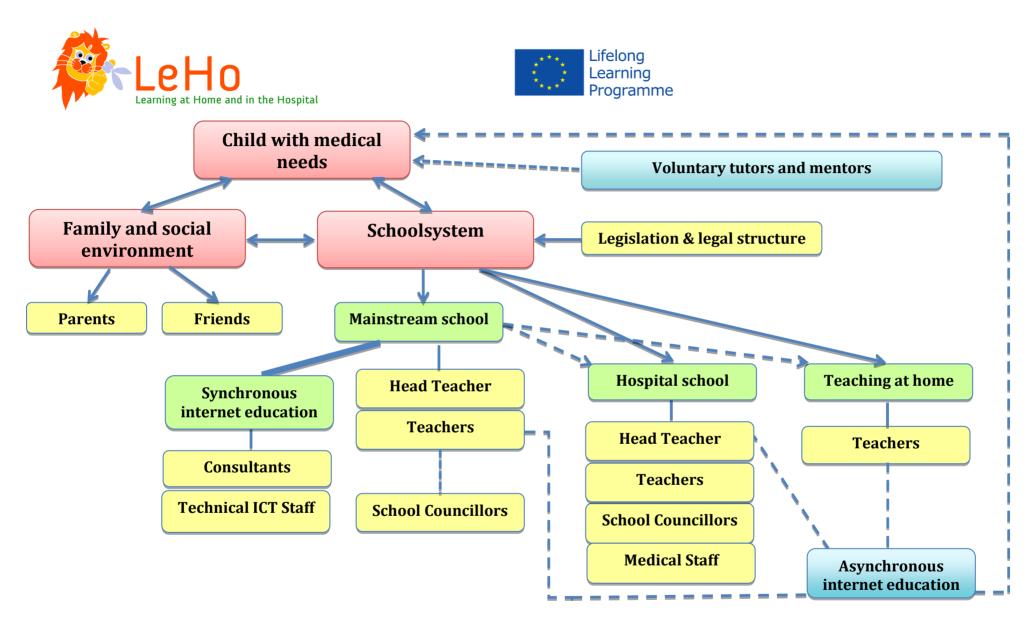


Figure 2. Those involved in the education of children with medical needs





Part of the answer to the above questions is described in the LeHo report, "Institutional Environments of HHE in Europe June 2015".

This report states that typical tasks in caring for pupils and students with medical conditions begin by making contact with the patient, the parents, the mainstream school, the responsible doctor, the nurses and the therapists, in order to gather information about the child's abilities and the limits of any likely educational approaches. An educational support plan that

A multidisciplinary team around a child with medical needs

outlines the objectives and tasks of all the participants of the interdisciplinary team can only be designed when the educational needs are known, along with the characteristics of the medical treatment e.g., the duration and location of the treatment, as well as the available learning time and resources. It is also vital to consolidate the faith in the patient's own future. Her/his education must enforce the will to survive, to get well, or if not, then the ability to come to terms with a lifelong illness. Realising the right to education for all individuals with medical conditions, whatever the setting, requires high quality, intense and continuous education, which must be ensured by the local institutions, i.e., the hospital school, home education, the mainstream school, or combinations of these.

The short and long-term effects of illness and treatment on the behaviour of pupils and students with medical needs will vary with the nature of the illness and treatment. The list may be long. An idea of what this looks like for cancer patients can be found in the book "What about School? A resource for parents and teachers of children, adolescents and young adults with cancer"⁶, an excerpt of which is shown below. Note that this is just a partial list and you should always check with the treating medical staff.

Short term treatment effects may include:

nausea, vomiting and diarrhoea

low energy levels e.g., fatigue and lethargy

changes in the child's physical appearance e.g., hair loss, weight loss or weight gain (this may include facial swelling)

abnormal hormonal function that may affect growth patterns

changes in appetite

dry skin, eyes and mouth, and mouth ulcers

increased vulnerability to infections

hearing loss - high tone deafness may occur after treatment with certain drugs

vision problems

seizures

heart problems – including reduced heart function resulting in shortness of breath, chest pain or palpitations and reduced tolerance for exercise

Long term treatment effects may include:

changes in the time it takes to process information and complete tasks

difficulty sustaining attention

memory difficulties

ongoing fatigue

sun sensitivity and other skin disorders

difficulty following instructions

learning difficulties

difficulty with fine motor skills

difficulty with planning, organising materials or solving abstract problems, often referred to as executive functioning problems





The documents describing the policy for pupils with medical needs that

As a school we will not:

 Send children with medical conditions home frequently or prevent them from staying for normal school activities, including lunch, unless this is specified in their individual healthcare plans.

- Send them to the school office unaccompanied or with someone unsuitable if they become ill.
- Prevent pupils from drinking, eating or taking toilet or other breaks whenever they need to in order to manage their medical condition effectively.
- Prevent children from easily accessing their inhalers and medication and administering their medication when and where necessary.
- Penalize children for their attendance record if their absences are related to their medical condition e.g. hospital appointments.
- Require parents, or otherwise make them feel obliged, to attend school to administer medication or provide medical support to their child, including with toileting issues. No parent should have to give up working because the school is failing to support their child's medical needs.
- Prevent children from participating, or create unnecessary barriers to children participating in any aspect of school life,

have been developed by mainstream schools may also provide some answers to the questions above. School policy on pupils/students with medical needs

The text in the box on the left comes from the Smithdon High School policy ⁷ for pupils with medical needs. The full document is naturally much more comprehensive, but it ensures a multidisciplinary collaboration within the school and between the school and those involved with the child outside of the school.

Although specifically formulated for a mainstream school, many of the policy items listed in this document can be applied to hospital schools, special schools and to mainstream schools that have to deal with a pupil or student with medical needs.

Take a couple of minutes to read the full document and reflect on the concrete responsibilities of the people involved, as well as on the instructions about how to act to support the collaboration.

Some hospital schools have developed comprehensive questionnaires to systematically collect information on the child's academic, pastoral and additional needs from the partners in the multidisciplinary team involved in the care of the child. This data provides the best start possible for the education in the hospital school, as well as monitoring the

Comprehensive questionnaires for the multidisciplinary team

progress of its pupils / students. One example are the Pupil Referral Form, Pupil Passport and Review Materials, produced by the Children's Hospital School, Leicester.⁸

In the **Pupil Referral Form**, which is completed by the referrer (i.e., the person responsible for or the reason why the child is being referred to the hospital school), personal information about the child (name, age, gender, ethnicity, current school) and contact information (parents or guardians, current school) is complemented along with curriculum information on the various subjects and information on the social status of the child (i.e., whether social services are involved, child protection issues, a risk





assessment), the reason for referral to the Hospital School, expected outcomes and anticipated length of stay. Attachment of a Medical Referral is an essential requirement of this section of the form.

In the **Pupil Passport,** essential information from the Medical Referral gathered, which includes a summary of the pupil's needs, an overview of the risks the pupil faces and poses, and a description of the pupil's behaviour in terms of causes and triggers. It is completed by the Children's Hospital School via visits to the pupil's home and mainstream school and through testing (base assessment of the student's academic status). This section also includes detailed planning of the pupil's education whilst in the hospital school.

In the **Pupil Progress and Review Materials**, records are made of the pupil's vulnerability, coping behaviours and resilience capabilities through observation by the hospital school's teachers and tutors and via the pupil's academic performances. This section also deals also with planning the end of the placement and any information is fed back to the pupil's mainstream school or to local authorities in case a relocation of the child is to be made.

Collaboration with parents and between those involved in the multidisciplinary team is essential for the educational process to be successful.

With the information provided in this section and in the linked documents, you should be able to answer the following questions:

For new HHE teachers:

- Can you design your own registration form? What information would you record? Do your answers fully or only partly match with those in the examples?
- Try to give reasons why you dropped, maintained or added (new) items.

For HHE teachers in practice:

• Does your school use similar registration forms? Do they match with the examples in this section? If not, why not? Would you propose any changes to your colleagues? If so, what arguments would you use to convince them?





Successful learning and Key Educational Factors (KEFs)

After having focused on the roots of the education of pupils and students with medical needs as reflected in the legislation and organisation throughout Europe, and considered this education in its similarities and differences with mainstream education, the fundamentals of learning and education



(Image:<u>https://www.flickr.com/photos/3758</u> 3694@N04/3457947874 Shared under a Creative Commons <u>CC BY-NC 2.0</u> licence)

must be considered. Learning is studied in terms of learning psychology and education in instructional design, whereby an important question deals with the transition from "description" (learning psychology – how do people learn) to "prescription" (instructional design – how to make people learn in an efficient and effective way). For HHE it is of even greater importance to consider the particularities of the child's illness and its impact on any behavioural consequences for those with a medical condition.

For a long time, it was considered that learning happened automatically provided the setting

Learning

and environment were right. In other words, the responsibility for learning was on the teachers and it was up to them to organise their teaching in such a way that learning would occur by itself (more or less). Learning was almost like a black box where you could control what was put into the box, and depending on the nature of this input, different outputs (learning effects) would occur. But what happened in the box remained a mystery.

Contemporary theories of learning have focussed on finding out what happens in that box: how is information collected by the learner, how it is processed, how is it stored and retrieved, how is memory organised for that purpose, and what is the role of motivation, etc. There are many different visions and theories about learning and how learning can be supported, and many websites provide an overview of various learning theories, that is explained at a non-scholarly level.⁹

Key Educational Factors

In line with the theory of social constructivism, a common theory in education, the LeHo project members identified a set of Key Educational Factors (KEFs) for the education of children with medical

Social constructivism for HHE: KEFs

needs at home, in the hospital and in mainstream schools.¹⁰ Learning is considered to be the construction of knowledge. It therefore assumes an activity on the part of the learner. The social aspect stresses that knowledge is being constructed during interactions within the context in which the learner is situated. It is this interaction that creates understanding and supports the development of skills. Six fundamental KEFs have been identified and these are:





A. Relationships

 Real learning can only take place through interpersonal interactions or interactions with the environment and its cultural artefacts.

Interactions with the environment and

- A learner is highly motivated to learn if challenged with problems that are situated in the "zone of proximal development", i.e., problems that are considered by the learner as being beyond their actual development level, but that can be solved with the guidance of adults or through collaboration with more capable peers.
- Education and learning are also influenced by factors that are relevant to the learner such as the
 immediate setting, the availability of tools and facilitators, the emotional climate in the classroom,
 teaching practices, technology, as well as by factors that are more distant, such as culture, systems
 of belief, the care network supporting the child and his/her parents and communication between
 different parties involved in the education of the child.

B. Making sense and constructing knowledge

 Learning a complex subject matter is most effective when it is meaningful and intentional i.e., when it fits into the goals that the learner wants to reach.

Active knowledge construction, meaningful for

- It is important that all the individuals involved (i.e., all those shown in Figure 2 above) always perceive the educational processes as being meaningful. Successive processes are more effective when they are continuous and stable.
- New information should always be linked to existing knowledge ("prior knowledge") and personal experiences in meaningful ways.
- Frequently, the emotional state and motivation of the individual and the group are influenced by each other.

C. Assuming roles

 Learners should be able to apply new educational achievements to novel situations and successfully assume new roles, which are recognised by teachers and their peers.

Acknowledgement of new roles during skills acquisition

• The learner should be able to use learned skills to represent and narrate his/her internal and external reality to others.

D. Metacognition

 Thinking, reasoning, organising, planning and controlling should alternate with things like acting, doing, building, drawing, making etc.

Understanding and regulation of

 Various materials should be involved in this process because they activate different thought and sensory experiences.





 Self-controlled and peer-controlled tools (checklists, forms, discussions) at different stages of the learning process enable the learner to become more responsible and independent during their learning process.

E. Individualities

 Learners have different learning strategies, approaches, and capabilities as these are functions of the individual's prior experience, social climate, motivation, culture, personal learning styles and development. Education must respond to these individual differences.

Typical aspects of individual learning processes

- Educational guidance and support by the provision of resources, templates, advice, task modelling, coaching ("scaffolding"), and formative assessment enable learners to achieve higher goals. This increases the learner's self-esteem (the learner's overall subjective emotional evaluation of his/her own worth) and self-efficacy (judgments about his/her capabilities to learn or to perform at the expected levels). Scaffolding fits into the concept of the "zone of proximal development" (explained above).
- Teachers should precede each learning process by a phase of listening to and assessing the learner's own history, desires, aptitudes, and culture.

F. Inter-institutional communication

Schools and parents are partners in the child's education. How
the child functions in their family, their effectiveness at school
and their success are aided by open communication between the
school and the families, and are influenced by school policies,
philosophies and practices.

Maintaining ongoing communication between all those

- Educational outcomes are empowered by good communication and mutual recognition between
 the different institutions directly involved in the child's education, as well as between local and
 national educational authorities. Tools for monitoring the students' progress must be shared and
 support such communication.
- Assessment of the students should include academic as well as personal and social developmental abilities. Shared evaluation and assessment documents should be used for these purposes and should be mutually recognised by the various educational institutions involved in the educational process.

The LeHo forum groups on five KEFs¹¹

Two rounds of discussion groups (Focus Groups: FG1 and FG2), consisting of teachers and groups of medical staff where organised in the partner countries of the LeHo project. They discussed the five KEFs with their own experiences in mind.

The voice of HHE





- 1. In your experience, what are the main obstacles to teaching children with a medical condition, either at home or in the hospital?
- 2. In your experience, what are the main factors enabling children with a medical condition to take part in school activities and to receive an education?

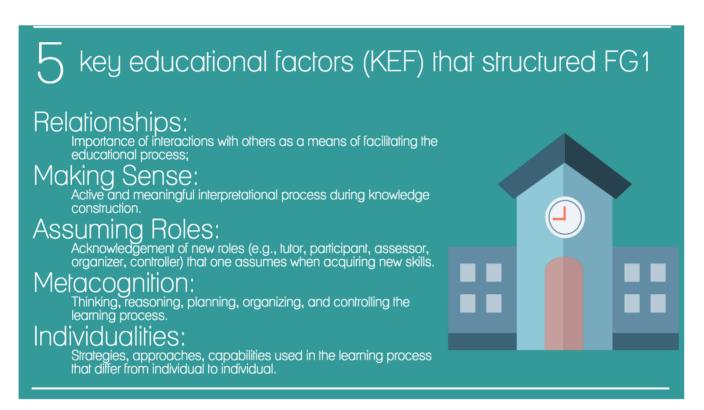


Figure 3. The five KEFs that structured discussions in FG1

(Taken from Capurso M. & J. Dennis (2015). Focus Groups. ICTs and Education of Children with medical needs. Final report. p. 6)

Global observations within Focus Group1 (FG1)

Making sense and constructing knowledge was the least important of the KEFs, according to the outcomes of FG1. From a pedagogical point of view this KEF is related to the ability to structure medium- and long-term educational projects with custom goals and a solid network of relationships.

Not surprisingly, the KEF recognizing the individuality of the student (i.e., "Individualities") was covered to a large extent by use of appropriate educational practices, given that most educational activities within HHE are individualized.

The **use of ICT**, which was investigated more specifically in the FG2 discussions, showed some interesting trends. One outcome was that the area in which the use of ICT is perceived to be more beneficial was in the KEF for "Making sense and constructing knowledge". ICT is therefore perceived as the tool of choice for creating a socio-constructivist environment that respects the needs of the child. Given the positive role of the "Individualities" KEF it is interesting that there are fewer statements





about the use of ICT in this KEF compared to all the other KEFs. Therefore, this suggest that ICT might be best thought of as a tool for keeping the child connected with his/her peers.

Summary of the most important observations for each KEF

Note that the KEFs themselves are not mentioned in order of importance.

Relationships

- Outcomes of the focus group discussions concerned the use of ICT learning tools for integration (contacts with classmates) and teamwork.
- Most problems concerned external psychological factors, isolation factors and stigmas associated with being ill.

Making sense and constructing knowledge

- ICT learning tools were most positively reviewed in the focus groups; specifically to create meaningful and constructivist activities.
- Most problems concerned the isolation that children with a medical condition faced and on insufficient communication between medical staff and teaching staff with respect to this KEF.

There is some irony in the fact that communication technology was not able to effectively solve the problems of isolation!

Assuming roles

- Most of the positive statements concerned integration and teamwork, for example an integrated educational environment, through forms of cooperative learning appears to be the ideal method to allow HHE learners to take up active roles in front of their peers.
- The major problems concern the stigma attached to being ill, and problems related to intrapersonal psychological factors.

Metacognition

- Most of the positive statements concerned the use of experiential learning tools and activities and the adaptation to the medical condition of the learner.
- Most problems concerned the difficulties to set up and perform effective metacognitive learning activities, due to issues relating directly to the illness (e.g. maintaining a sterile environment around the child and safety) and the lack of financial resources to combat these.

Individualities

- Recognition of each student's individuality is adequately covered by the existing appropriate
 pedagogical practices (e.g. adaptive teaching and guidance, communication, systems of selfevaluation and assessment, and attention to integration).
- Problems identified relate to the sharing of practices and procedures with the child's mainstream school, or are linked to the rigidity of the mainstream school's assessment procedures when dealing with the hospital school.





The influence of the learner's medical condition on learning, in terms of the KEFs

A. Relationships

Children with medical needs tend to focus on their illness and its consequences (e.g., they experience a loss of capabilities, uncertainty of the future, pain that hinders concentration, extreme fatigue and reduced effort) resulting in reduced motivation to acquire new knowledge and abilities. They need incentives and stimuli from their classmates and teachers to be challenged and motivated.

The problem is that whilst they are ill, they often have a weaker social bond with their classmates, as

(Image: <u>Steve Spinks</u>. Shared under a Creative Commons <u>CC BY-NC 2.0</u> licence)

their illness often prevents them from participating in the social activities of the class.

The education of children with medical needs in a hospital school or in home education is often a one-to-one relationship between the learner and the teacher. This makes it more intensive than the relationship between learners and their teacher in a classroom situation. The one-to-one relationship with an adult instead of a many-to-one relationship with their peers has different effects on experiential learning and inhibits group learning and community building activities.

Children with a physical illness often have difficulties in talking openly with their peers about their illness and also

with the often visible effects of their treatment (such as hair loss in cancer patients); for those suffering from mental and psychiatric illnesses, it can be even harder, as these often carry a stigma.

Some illnesses and treatments in which the brain is affected often result in behavioural differences that affect relationships: they may behave in a way that is rather antisocial or have difficulty in acknowledging that their behaviour is a problem, or they may often lose their train of thought which can manifest as difficulties with verbal expression.

However, no matter what the best efforts of the teaching staff (be it in home education, hospital school or mainstream school), these will be far less effective if collaboration between parents and medical staff is missing, and this is especially the case for children from underprivileged backgrounds. This collaboration has to be bidirectional. Teachers need the support of all those involved in the care of the child to collect the necessary information about the child's condition and capabilities and to encourage the child's motivation. Parents and medical staff need information from the teachers about their pedagogical approach, the learning tasks and the efforts needed to provide this support.

B. Making sense and constructing knowledge

Making sense is closely linked to the goals and aims of the learner. Any activity, effort, mental construction, focus or concentration only makes sense if these contribute towards the learner reaching their targeted objectives. As illness may create uncertainty with respect to the future, and pain and immobility can force a child to focus on the immediacy of their illness and treatment, it is understandable that learners with medical needs struggle to meet this KEF.

There is a similar problem with constructing knowledge. Knowledge construction is not an automatic process, as it needs the learner to be active and to make an effort and persevere.





To counteract these issues, teachers should first combat the isolation of the child. Classmates can also play an important role here, and especially when they are engaged in the active support of the child with medical needs (e.g., by chatting, acting as a go-between to pass on information, assignments, home work, etc. from the mainstream school to the ill child and vice-versa). Certain tools which can help to establish and maintain this communication have been developed over the last few years, for example, initiatives such as Monkey in my Chair, WebChair, making robots, etc. They are discussed in Tools for communication.



http://farm8.static.flickr.com/7378/8720604364_85c5 931a14_m.jpg. Shared under a Creative Commons <u>CC</u> BY-NC 2.0 licence)

Some commercial technologies are also helpful. They facilitate communication, are often already

used by young people, and can be easily tailored to subject matters to suit each individual (see <u>Tools</u> <u>for communication</u>).

C. Assuming roles

Assuming roles implies mental flexibility and sustained concentration; and depending on the role to be assumed, abstract reasoning and concept building will also be come into play. These skills may be affected negatively by illness and hospitalisation.



(Image: <u>CJ Sorg</u>. Shared under a Creative Commons <u>CC BY-NC 2.0</u> licence)

Similar to making sense and constructing knowledge, assuming roles in front of others is also somewhat out of the scope of learners with medical needs, as this can often be impossible due to the isolation faced by children in a hospital or at home, and also by the stigma the comes with being ill. For this reason, these children especially need the help of their peers, teachers and medical staff as well as their parents to encourage them to develop these skills.

However, often it is the parents who hinder the development of their children by being over-protective and keeping the child reliant on them. Some parents also become involved in the pedagogical setting of the

teaching and learning. They forget that an ill child must also have time to be a child and as such, may have issues that they only want share with their peers and perhaps their teachers, rather than with their parents.

Sometimes the teachers hinder the development of the child by becoming too involved emotionally, or by preventing input from the parents who they see as disrupting the learning process.

In an HHE environment, the use of cooperative learning formats can be an important tool to initiate and promote assuming roles. As cooperative learning addresses small, heterogeneous groups of learners that jointly complete problems and projects, it challenges learners to take up new roles and





reinforces the learner's own learning as well as the learning of the fellow group members. More information about cooperative learning and on formats it can take is to be found in Heather Coffey's articles on Learn $NC.^{12}$

D. Metacognition

Metacognition includes planning and organisation, self-awareness and self-monitoring. In most cases of serious illness, these skills are affected.



(Image: https://en.wikipedia.org/wiki/Portal:Thinking#/ media/File:A_woman_thinking.jpg. Shared under a Creative Commons CC BY-SA 3.0 licence)

Even in a mainstream school situation, metacognition is a KEF that is underrepresented. Many teachers are still more concerned with factual knowledge and skills than with thinking, planning, reasoning, organising and controlling. Teachers often hesitate to engage with this KEF, especially when these "meta"-cognitive aspects of learning (literally aspects that go "beyond" with cognition) have to be placed at the centre of the focus, monitored and assessed, and this is much harder than providing knowledge or training skills, and the assessment of these.

Metacognition is aimed at long-term outcomes and parents are often more interested in the immediate academic success and promotion of their child to a higher class at the end of the year than in learning things that will only have dividends later on. And teachers have to

take that into consideration.

Therefore, being realistic and remembering the often problematic relationship with the future that learners with medical conditions may experience, it is likely that this KEF is much more difficult to implement in HHE than it is in mainstream education. However, when the child returns to their mainstream school, this KEF should be borne in mind, as the effects of illness persist and take time to be dismantled.

E. Individualities

This KEF is already well covered, both in HHE and in mainstream schools. However, it is the approach that differs between these two types of educational setting. In an HHE context, the individuality of the learner must include the medical condition and its effects on learning, whereas in mainstream schools individuality is more often considered in terms of the development of cognition, abilities and skills. The dynamic and effective aspects of the individual's personality (motivation and especially emotionality), which are

very important for a learner with medical needs, tend to be somewhat overlooked in mainstream schools and consequently have less influence on their assessment.



(Image: <u>Vaughn Saball</u>. Shared under a Creative Commons CC BY-SA 3.0 licence)





Information for a teacher of a learner with a medical condition

The following suggestions were made by participants of the first Focus Group discussions on the KEFs. They should however be applied with caution, as pedagogical interventions may work differently depending on the pupil/student characteristics and concrete environmental circumstances.

Behavioural and medical sciences often base their research on observations (behaviour, attitudes, symptoms, syndromes, the evolution of disease and treatment, etc.). To investigate the effect of an intervention/treatment, a comparison is made between the observations both with and without the intervention. It is thus easy to conclude that any differences found are due to the intervention. However, research on "mediators" and "moderators" warns that things may be more complex than they appear. A "moderator" is an influencing factor that states on whom, or under what conditions, an intervention/treatment produces its effect. A "mediator", in contrast, states how and why a treatment produces its effect. Research on children with medical conditions had considered four educational mediators and moderators:

- 1. Type of illness
- 2. Country specific culture and support services
- Age
- 4. Type of school service provided.

To illustrate this point: the ability to solve arithmetic problems will be influenced by the pupil's age (the moderator). The younger the pupil, the more difficult it will be. However, this ability can be enhanced or reduced by the type of learning support (the mediator) that is offered.

In other words, it is important to consider these mediators/moderators when making any changes or applying interventions. The following should be considered;

- Pay close attention to the child's physical and psychosocial development
- Try to further the learner's education as far as possible, taking into account the limits that are imposed by illness, treatment or aftercare
- Organise their education with an emphasis on continuity: if the child is in a hospital school or receiving home education, aim to follow, as much as possible, the objectives and approaches of the learner's mainstream school, and prepare them, as much as possible, for their potential (later) return to their mainstream school
- Maintain contact with the parents to remain informed about their concerns and the learner's state
 of mind. Keep them informed about their child's progress, explain your educational approaches and
 provide them with information about how they can help to motivate their child and support his/her
 education during their illness and aftercare
- Maintain contact with the medical staff, the mainstream school staff and the eventual support network of the child. A purposeful exchange of information is paramount
- Provide possibilities for the learner to stay in touch with his/her classmates in their mainstream school





This information, aimed at HHE teachers should be applied in your main teaching plans. Think about your lesson preparation, the way you intend to approach the learner and how you will communicate and evaluate your learners and their context.

Think about the communication with parents, medical staff and teaching staff in the mainstream school: what types of information do you or would you normally exchange with them? What kind of information would you only share with your colleagues in the hospital school or in home education?

Discussing your answers with your colleagues may provide new and refreshing insights that are beneficial for all.

Having done so, compare your answers with the specifications that are given below for the different age groups.

Supporting children aged 2 – 6 with medical needs

Children are naturally eager during their early childhood to explore their living environment and their own body and its capabilities. They learn by observation, imitation, repetition and especially by doing. Teachers of this age group must support this urge by creating a learning environment that is safe, extremely varied and rich in physical and

Learning by observation, imitation, repetition,

mental stimulation, for the child practice their motor skills, verbalise these actions ("tell me what you are doing / making") and stimulate the natural creativity of the child. Collaboration (playing together) should also be actively encouraged to enhance their motivation.

Children with medical needs are confronted with an environment that poses restrictions. Their motor development is often hindered by physical confinement, and their social contacts are equally restricted. Furthermore, the environment is less rich in challenging possibilities for learning and their illness and treatment can lead to apathy, a reduced concentration span and fatigue.

However, education for this age group is mostly based on play, with less emphasis on demanding



(Image: © Bednet vzw (http://www.bednet.be/))

learning, and this allows for a classroom setting in which there is room for a group of learners with very different levels of capabilities, skills and development, to enjoy playing with each other. It has also been observed that many young children with a medical condition have an increased level of empathy and maturity that is often ahead of their peers. For example, they often spontaneously help others without being asked and stand up for other children that are being teased.

In home education, a one-to-one educational environment replaces this open setting. As far as the





teachers are concerned, quite often they replace play with more formal learning activities. It must be remembered, that as a teacher in this scenario, you are dealing with learners with a medical condition that not only have the right to an education, but they also have the right to be feeling unwell.

Supporting pupils aged 7 – 11 with medical needs

During this period, children change rapidly. The first years of this age group can be considered as an extension of early childhood:

Extension, deepening

- There is further development of the fine motor skills and language (vocabulary, sentence construction in spoken and written language)
- Temporal and spatial orientation extends
- Self-image and identity is explored
- Elementary use of abstract constructs and reasoning (counting and elementary arithmetic) become possible, but is still closely linked to manipulating real objects
- Real friendships and broader social contacts (e.g. in youth clubs) gradually extend the social environment of the family.

Along with these increasing capacities and capabilities, there is a higher level of demand in their learning and education. However, for children with a medical condition, the main points to be considered regarding education are largely the same as those for the ages 2-6.

The last years of the 7 - 11 age group constitute a bridge to early adolescence:

 Growth and maturation go hand in hand with increasing selfawareness of their own strengths and weaknesses through comparisons of their own capabilities and performance with their peers Exploring complexity in knowledge, skills and emotions

- Real abstract constructs and reasoning become integrated with reality
- They begin to take their own initiatives and develop a sense of responsibility
- Growing self-awareness enables monitoring of their own behaviour and as such is a prerequisite to the development of metacognition
- However, at the same time hormonal changes cause emotional disturbance and uncertainty, for which support is needed from trusted people such as parents and family, teachers and good friends.

It is obvious that illness and treatment have a serious impact on this development. Isolation and limitations



https://www.flickr.com/photos/afferdenlimburg/8681503824.Shared under a Creative Commons CC BY-NC 2.0 licence)

to contact with their peers slows their development and the quality thereof. Medication and medical care can disturb the normal hormonal changes and cause additional side effects.





However, on-going support is needed with abstract concepts and the manipulation thereof. This is clearly relevant for maths, but also in more formal approaches in other subjects. Teachers should stimulate and guide their pupils to make mental representations of reality and frequently practice manipulations of these to create abstract concepts. Problem-solving strategies should be introduced, again starting at a concrete level and practiced in small steps.

Teachers should remain patient with their pupils, as abstract reasoning and problem-solving are difficult issues and illness inhibits their development.

Help is also needed to introduce (elements of) metacognition. Having an "objective" view of one's self is not trivial and young people must be carefully coached in building this up. Their feelings should be explored and they should be given frequent positive remarks as stimuli for motivation. As a teacher of children with medical needs you should avoid discouraging your pupils, but at the same time teaching must be maintained at the level of the "zone of proximal development".

Supporting students aged 12 – 18 with medical needs

Adolescence bridges the gap between childhood and the adult world. It is the time in which adolescents can deploy the various facets of their developing personality and experiment with their capabilities in a safe environment: they have the freedom to act and to take responsibility as long as they respect the freedom of others.

Independence, emotional maturity, self-awareness, self-

Major aspects of this adolescent behaviour are:

- Independence; adolescents want to make autonomous decisions, which regularly leads to conflicts with parents (and teachers, as they are inclined to dispute authority) and question adult expectations
- This desire for independence often leads to risk-taking behaviour (e.g., on the street, but also in provocative speech and attitudes in classroom situations)
- As much as they claim their independence, they are influenced by the opinions and behaviour of their peers (using typical slang, choosing the same clothing, listening to the same music, etc.)
- In line with this, they develop interests that are common with friends and teammates. Such social contacts and their developing emotional maturity often lead to relationships with a special partner, and sexual activity for some
- Cognitive and psychosocial development help them become aware of their own identity and lead
 to greater self-awareness and self-esteem, which influences their academic results in both positive
 and negative ways depending on whether they are feeling good, worried or anxious. At the same
 time, it enables further development of their ability to reflect on their own learning processes and
 helps to learn planning, monitoring and evaluation of their learning and thinking processes.

A medical condition clearly has severe influences on these processes and development. As with other educational levels, a diagnosis of illness provokes direct changes in the behaviour and capabilities of the student, but also indirect changes that are connected to the reactions of parents, family, friends, medical staff and teachers. The difference between adolescents and the other age groups is that they are already

Effects of the medical condition on the subject-oriented education of students





concerned about their future and are capable of estimating what the impact of any illness might be on their expectations. Some will react with anxiety, depression or stress, others will be rebellious, but it is also possible that they will mature more quickly.



(Image: Shared under a Creative Commons CCO public domain licence)

Classes in this age group are taught by subject-specialised teachers, many of whom are very enthusiastic about their subject and try to pass this on to their students. Some teachers even believe that their subject is the most important one on the curriculum and expect their students to achieve accordingly.

HHE teachers on the other hand have daily experience of the consequences of a medical condition on the achievements and attitude of their students, and are regularly confronted with mainstream school colleagues who are incapable of accepting these limitations. For example, when asked by the

HHE teacher for guidance about the main subjects the ill student should cover before their return to mainstream school, the replies are often along the lines of "they have the whole day to study, why restrict their education to a subset of subjects or just the most important ones?" or "why do they only have lessons for a couple of hours a day?" They seem to be deaf to the arguments about how treatment is prioritised over education and believe that the psychological effects of illness and treatment are exaggerated and used as an excuse for what they consider as underachievement. Imagine the frustration of the HHE teachers, knowing that in some countries they are only allowed to provide information about the student achievements and learning attitudes, but that the final evaluation and decisions are made exclusively by the mainstream schoolteachers.

Another frustration in the relationship between HHE and mainstream schoolteachers concerns teaching and learning materials. Many mainstream schoolteachers produce their own materials and some are not prepared to share them with their HHE colleagues (sometimes they even refuse to share them within their own school).

This is another reason why it is vital for HHE teachers to maintain contact with the teaching staff of the mainstream school of their students. The size of class groups in hospital schools automatically leads to a more restricted number of (multidisciplinary) teachers and the eventual adaptation of the curriculum. Needless to say that a protective attitude about sharing teaching resources hinders both learning in the HHE environment and the eventual smooth return of the pupil to their mainstream school.

It often requires a great deal of diplomacy to turn such an unfavourable situation into an acceptable one, and skilled HHE teachers should help their younger colleagues to resolve these types of issues.

It is not only the medical condition of the learner, but also the use of subject-specific classrooms (labs, computer classes, technical workshops, etc.) that can lead to adaptations in the curriculum. Not every classroom type that is used in mainstream secondary education can be replicated in a hospital school environment. All those involved in the care and education of the students, as well as the student themselves should be included in decisions concerning their education provision while they are ill, and even then, a creative and flexible (multidisciplinary oriented) attitude of the hospital teacher will be needed to teach the practical aspects of the curriculum in the hospital or home environment.





Profile of an HHE teacher

To our knowledge, there exists no complete European profile of an HHE teacher. Otto Mourik developed a professional profile for hospital teachers in the Netherlands, which listed the essential characteristics required in terms of tasks and competences.¹³ The list is structured into three blocks. On the most general level (Task level A), the competences commonly

Tasks and competences of HHE teachers

needed for all professions in which highly educated professionals operate, are listed. The middle level (Task level B) lists the competences needed to cope with general tasks and subtasks in the support field, independent of the actual position that is to be filled. This level corresponds to the characteristics needed by all those involved in education to support individual pupils, teachers and teaching staff, and to be able to discuss issues with parents, medical staff and to cooperate with external organisations. The level of the most specific tasks (Task level C) lists the competences for the typical activities of teaching and the educational support of learners with medical needs, with the emphasis on the characteristics needed by hospital teachers. These characteristics encompass the ability to cope with a variety of social and cultural differences, to work independently, to use individual action plans and to develop individual educational arrangements.

However, there is one important fact to note; the overview was made with hospital teachers in mind for learners suffering from (psycho-) somatic diseases; children and adolescents with psychiatric or/and behaviour problems were not specifically covered.

Before viewing the overview, it is important that teachers consider the comments below in this light.



(Image: <u>Jason Kasper Harisburg</u>. Shared under a Creative Commons <u>CC BY-SA 2.0</u> licence)

HHE teachers normally include more than just the hospital teachers. Teachers in home education work in a different environment, although with many similarities to the educational setting of hospital teachers, and also frequently have to deal with individual learners or very small groups. Most of the required competences in the overview will therefore be equally valid for HHE teachers. Although tutors and those in learning support (such as teaching assistants) do not have the same responsibilities as teachers in a hospital or at home, they should have similar competences to provide effective and

efficient support. Hence it is not surprising that many are former teachers, who have changed their jobs to ones that provide more support than teaching.

The competences of teachers in mainstream education are somewhat different. The general professional and supporting tasks (and to a certain extent even the specific tasks) are largely the same and require the same competences, even when the learner characteristics differ between pupils and students with and without medical needs. Furthermore, the multidisciplinary

And what about mainstream school teachers?

mix and the nature of the remedial teaching in the educational setting are not the same. However, the tendency in an increasing number of countries to move from a dedicated educational setting for learners with medical needs towards more generic education provided by, and under full responsibility of, the child's mainstream school (and to which he/she would return), implies that mainstream school





teachers are also increasingly confronted with learners with a medical condition. In most cases they are never really prepared for such a situation, not during their academic training nor in their continuing vocational training. A possible solution can be seen in the Dutch example. When new legislation with respect to the education of learners with medical needs was implemented in The Netherlands in 1999, responsibility for these learners was completely given over to their mainstream school and the hospital schools were closed. Mainstream schools had to provide so-called "inclusive" education and former hospital teachers were appointed as consultants to support the teachers in mainstream schools to teach "inclusive" classes and to support learners in home education situations.

While reading the collection of tasks and the corresponding competencies (below), you should consider and discuss with your colleagues, the relevance of the competencies mentioned and think about real examples / behaviours in your teaching that are connected to the various tasks. Mourik's book elaborates on the various tasks as well as on examples of the corresponding behaviour of teachers. You should compare your answers with his descriptions.

Task level A. General professional tasks

A.1 Act as an individual professional

Competence 1 Be involved with society at large (its various facets and people)

Competence 2 Develop and implement a concept of duty

Competence 3 Act according to your values and identity

Competence 4 Develop and implement problem solving abilities
Competence 5 Develop and implement communicative skills

Competence 6 Develop your own professionalism

A.2 Act as a member of a developing organisation

Competence 7 Participate in developing the organisation

Competence 8 Be part of the implementation of strategic policy regarding content

Competence 9 Work in an interdisciplinary manner

Competence 10 Participate in consultation

Competence 11 Give and receive collegial support

Competence 12 Report to and be responsible to management

A.3 Act as part of a professional team

Competence 13 Cooperate on a professional level Competence 14 Develop professional qualities

Task level B. Supporting tasks

B.1 Task as a supporter for teachers/schools

Competence 15 Hold discussions with teachers

Competence 16 Determine the need for any support

Competence 17 Realise individual support for a pupil





Competence 18	Diagnose	prob	lems
---------------	----------	------	------

Competence 19 Assist with the making and implementation of action plans

B.2 Task as a discussion partner for parents

Competence 20 Hold discussions to clarify problems

Competence 21 Hold advisory conversations
Competence 22 Build up a relationship (of trust)

B.3 Task as a supporter for pupils

Competence 23 Diagnose specific problems

Competence 24 Motivate the pupil and call on support if needed

Competence 25 Set up, adjust and possibly implement didactical support

B.4 Task as a case manager

Competence 26 Coordinate support

Competence 27 Acquire knowledge about the case

Competence 28 Set up a plan of action

Competence 29 Report interim and end results

B.5 Task as an adviser

Competence 30 Be informed about recent developments and keep up to date

Competence 31 Provide interested parties with written information Competence 32 Provide interested parties with oral information

Competence 33 Refer potential clients to third parties
Competence 34 Publish articles about new developments

B.6 Task within a multidisciplinary team

Competence 35 Deal with differences in tasks and concept of duties

Competence 36 Know and occupy a position in a multidisciplinary team

Competence 37 Make contact and keep up to date with educational support

Task level C. Specific supporting tasks

C.1 Task as an educator

Competence 38 Take educational responsibility

Competence 39 Take responsibility to create an optimal educational climate

Competence 40 Allow for social and cultural differences

Competence 41 Recognise questions of (social) educational concern

C.2 Task as a remedial didactic teacher

Competence 42 Utilise the possibilities for independent working

Competence 43 Design individual educational arrangements

Competence 44 Be able to complement different methods

Competence 45 Give effective instruction

Competence 46 Use adapted methods and techniques

Competence 47 Take responsibility for fitting in class management





Competence 48 Take responsibility for embedding in a system of pupil records

Some additional lessons learned from the Forum Group discussions in the LeHo project

Many teachers have difficulties in adapting their expectations and standards or to change their own teaching styles to match their colleagues'. The school culture is very important in this matter: during their teacher training, novice teachers learn

Be flexible

that observation and collaboration with more skilled colleagues is rewarding and thus they begin their career full of enthusiasm and willing to work hard and to apply everything that they have learned to date. If they are then confronted with "older and wiser" colleagues, who are somewhat suspicious of this enthusiasm and in fear that it may reflect badly on their own teaching, they may try to curtail the activities of the novice teacher. What follows then is a rapid decline into a more rigid attitude towards expectations and standards.

Teachers often act like small retailers; they tend to make their own agendas without consulting others and then expect everyone else to agree and to adjust accordingly. In creating their own solutions they are behaving

Be collaborative

like novices; without first exploring the available solutions they start experimenting and often come up with shortcuts instead of efficient and effective solutions to the problem. Regular consultation with more skilled colleagues and others involved in education is therefore a must.

With this in mind, HHE teachers should not restrict themselves to what colleagues in HHE have to say. Teachers in special education are used to being flexible and creative. They have learned in their everyday practice to leak for solutions that lie outside of everyday padagagy, and say provide

Take a look over the fence

to look for solutions that lie outside of everyday pedagogy, and can provide good practices that can be applied in HHE.

Teachers are sometimes put under pressure by parents to solve problems that are not their responsibility, and this occurs not only in HHE, but also in mainstream schools. It is important that teachers do not to fall into this trap. Not only does the teacher end up with more work to do, but more importantly, this is ultimately not good for the relationship between the child with a medical condition and his/her parents and can disturb the ongoing healing process.

Mainstream schoolteachers should inform the class about the medical condition of their classmates. It is important to be open and honest about the condition and its effects on learning, emotion, ability and motivation. Such information creates understanding and stimulates the real desire for the classmates to help and maintain communication with their absent friend.

Inform the class about the medical condition of their classmate

However, before providing this information, it is important to obtain agreement of the ill child and his/her family (how much information is provided and what kind of support can be provided to the ill child and to their classmates if the information might upset them).





At the end of this chapter, we suggest you review your reactions to the previous suggestions for reflection and discussion. Have you gradually changed your opinions, have you come to any new insights, have you reorganised your priorities, do you foresee any problems with your actions, do you think your school and its organisation needs changes and which facilitators and moderators could affect these changes?

Choose the five most important elements and try to implement them in your pedagogical/didactical planning and behaviour. Review them within several months' time to evaluate their value.





ICT and the education of children with and without medical needs

The potential for ICT in education

As a teacher, it is important to know which ICT tools are available and how they should be applied in your particular situation. To help you to do so, more general information about the media and ICT, as well as the results from the second round of Focus groups on ICT are shown below. The information is intended to help you evaluate particular tools and their values to your practice. Read it and then state your arguments in support of your position towards the statements that are made in the box at the end of this chapter.

ICT has drastically changed education. It has built on the existing use of media in education, and has provided the means for teachers to introduce elements into their teaching that would normally be too small or too big, or too dangerous to bring into the classroom, or to show processes that run too slowly or quickly to be observed in reality, or to challenge pupils and students with information about distant places, and to experience adventures that lie beyond their horizons. A variety of dedicated devices (hereafter, "media") are needed for this purpose and this has, in turn, meant that the use of media use can be costly and sometimes cumbersome.

The introduction of "personal" (desktop) computers changed this situation fundamentally: a single device provided access to multimedia applications (the all-in-one presentation of information that previously required the use of a number of separate media), and a little later also to hypermedia (applications with content that automatically, or under user control, linked to other applications or information). The next step was the development of the Internet and the World Wide Web. This had an enormous impact: it constitutes a vast repository of information that can be accessed efficiently and is often attractively presented to invite and motivate people to use it. For the very first time, teachers were able to individualize their teaching cheaply and easily and could produce teaching materials that would take account of the increased learning levels of the learners.

Next, Web 2.0 and social media arrived on the scene: teachers could not only download information, but also upload it and interact with others, sharing information and taking part in communities with shared interests by jointly "liking" the content. In an educational setting, this could be used to invite learners to interact with the materials actively and consistently, and also to communicate with the teacher and each other (if needed).

Mobile systems extended these capabilities to usage that is independent of place and time, and which has undoubtedly contributed to their popularity. Web 3.0 combined separate elements of Web 1.0 and





Web 2.0 into semantic networks (where texts, pictures, audio, video, etc. are semantically interconnected), stored in a "cloud" along with small applications (production tools) that activate data processing and data exchange between mobile systems, desktop systems and users.

The envisaged next development is the inclusion of artificial intelligence, the use of virtual reality and robotics. This opens up an expanded emotional dimension to informatics and communication, and the self-developing (artificial) "intelligence" of the computer. It is expected to completely change the user interface of future ICT devices and applications.

This evolution of ICT use in education has taken place over the last 50 years, and it still is ongoing; it is not the result of educationalists and teachers building up a new pedagogy and didactics, but is instead driven by the economic interests of hardware and software companies that produce materials for industry and consumer markets. Happily, education can also largely benefit from the results, at least when these are applied in a smart way.

Therefore, the question is, "what is the smart application of ICT in education?"

The media debate

In 1994, two American specialists in instructional design, Richard Clark and Robert Kozma, started the famous "media debate".

Method vs. media

According to Clark, "media are mere vehicles that deliver instruction but do not influence student achievement any more than the truck that delivers our groceries causes changes in our nutrition".



(Image: <u>Wesly Fryer</u>. Shared under a Creative Commons <u>CC BY-2.0</u> licence)

For Clark, it was not the media that had an effective influence on learning, but rather the teaching methods and the use of "authentic" problems or tasks. Authentic means that the learners consider these problems or tasks as relevant in their daily lives or future learning, to achieve personal goals or for application in a later profession.

Kozma disagreed with this position. He states that certain media "possess particular characteristics that make them both more and less suitable for the accomplishment of certain kinds of learning tasks".

For Kozma, the question was not whether the media influenced learning or not, but how the characteristics of specific media could be used to influence learning for

particular students, within specific tasks and topics, and under which conditions.

This debate concerns the teaching method versus the media used. Giving (too much) credit to the media in influencing student achievement may lead to a situation where students have to adapt to the requirements of the media, instead of the media being instrumental in the teaching methods and to the teacher's role in instruction. However, on the other hand, why should media be different from other didactic methods? There is no one thing in pedagogy that works for every situation, for every learner, and all the time. Media as a tool are vehicles for instructional method and needs to be chosen carefully according to precise instructional goals, learner characteristics and circumstances.





Is this debate still valid for today's learners?

Not only has the media evolved over time, but so have the learners.

Today's learners have grown up in a digital age. They readily use the Internet when searching for answers before asking their peers, parents,

The digital society

or teachers. They are surrounded by computers, cell phones, digital games and social media every minute of every day. They record their lives on YouTube videos, and by tweets and Facebook, etc., and use the World Wide Web, not just for entertainment or social networking, but also as an educational resource. Even before opening a book in search of an answer, they surf the Web, and their digital skills, along with the intuitive interfaces of digital media, allow even very young children to benefit.

It is obvious that this digital habitat has also changed the traditional roles of teachers and students.

To reach today's learner, teachers must include technology otherwise the learners will seek it out for themselves, because the Internet contains billions of "teachers" and its content is still growing. Even if teachers don't particularly like it, they need to embrace this fact because it is here to stay. As a consequence, being familiar with the educational use of ICT is a necessity.

The potential of ICT for the education of children with medical needs

What is true for all teachers is even more important for those involved in the education of learners with medical needs. The medical condition causes practical problems for which ICT tools can often provide an effective solution.

During the second round of Focus Groups (FG2) for the LeHo project, which investigated the attitudes of teachers and medical staff towards technology and their use of ICT, the following issues were discussed.¹¹

LeHo's second Focus
Group on ICT

- 1. Which ICT tools are used the most was the topic in 57% of the discussion items
- 2. In 17% of the discussion items was focussed on the problems that were experienced with ICT
- 3. Which and how ICT tools was considered as a help came across in 16% of the discussion items
- 4. ICT also has its limitations. Remarks about these were made in 9% of the discussion items.

Considering the variety in age, curriculum and study level of the pupils being taught/treated by the FG2 participants, it could be expected that the most used ICTs were not those specifically developed for education, but were instead commercial tools. Out of the total 278 ICTs that participants of the FG2 mentioned, 90 distinct ICTs were listed, including Email (14), Skype (14), Bednet (10), PowerPoint (8), Dropbox (7), Word (7), Excel (7), Publisher (6), Robotica (6), and WhatsApp (6).

How these ICTs were used resulted in 17 distinct categories, including: Software as a learning tool (31.3%), Communication/Information sharing (14%), Increase knowledge about the illness (9.4%), and Integration (9.4%). Mentioned less were: Active/creative learning, Administration, Distance relationships, Personalised learning and training, Device as a learning tool, Psychological factors, Autonomy, Monitoring, Teamwork, Orientation, and Privacy factors. In approximately 70% of the cases ICTs were used daily or almost daily.

The four main problems associated with ICT use in HHE were Technical factors, Administrative problems, Equipment feature and Connectivity factors. Interestingly, the most negative statements came from representatives from the hospital environments that were involved in the treatment and





care of the children. The problems appear to be partly institutional and organisational in nature. It is, however, more complicated to interpret the loading placed on factors concerning isolation, since ICTs are often considered as the optimal solution for combatting isolation in children with a medical condition. Could it be that the ICTs used (which are often productivity tools intended for the consumer market, as mentioned above) are insufficiently embedded in the broader pedagogical and psychological context of the HHE educational environments? Adopting or even developing ICT solutions that take insufficient account of the needs of a child with a medical condition may create problems rather than solve them.

However, the top 4 areas where ICT can make a difference in HHE are: Communication and information sharing, Software as learning support, Integration, and Personalized learning. They focus particular on the KEFs of Relationships and Making sense and constructing knowledge.

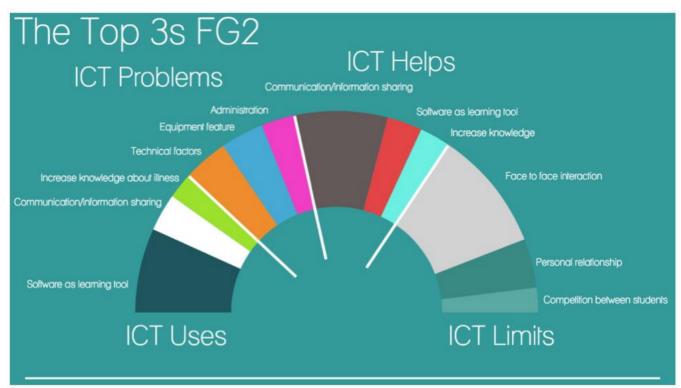


Figure 4. The main issues relating to aspect of ICT use as identified during the FG2 discussion (Taken from Capurso M. & J. Dennis (2015). Focus Groups. ICTs and Education of Children with medical needs. Final report. p. 35)

The FG2 also discussed the limits of ICT in HHE. The FG participants all identified that ICT could not replace the close, physical, face-to-face relationships with people. Even the use of videoconferencing applications can only support face-to-face contact, it cannot replace it completely.

How can ICT be used effectively?

Initially (from the mid 1980s - 1990) the educational use of computers was split into two categories: (1) learning by computer, and (2) the computer as a supporting tool for learning.

Learning by computer (1) encompassed every instruction were the computer replaced the teacher for knowledge acquisition. Through relatively simple courseware of a type that represented "programmed"

Learning by the computer





instruction", students were expected to learn new knowledge more efficiently. Programmed instruction was applied in a paper version before the computer was used. In its most simple format, the full body of information that should be learned was broken down into smaller units. Each unit was presented to the learner, after which a question about its content was evaluated to ascertain whether the expected learning had taken place. If the learner could give a correct answer, the programme replied with a "reinforcement" (reward) such as "very good", "you got it", "splendid", etc. However, if the learner gave a wrong answer or could not answer the question, the programme replied with a "punishment": the information was presented again, until the correct answer would be given.

Thus, it can be seen that the computer programme can perform better than a paper version of the programmed teaching. The computer allows much more flexibility: it can randomly choose reinforcement clauses (and formats of a multimedia type) from a larger collection, and is able to switch to alternative sections to correct wrong answers or learner misconceptions which initially led to the wrong answer.

Learning with the computer (2) was originally restricted to "drill and practice": e.g., math exercises for initial calculus. The computer was again preferential to real teachers, as the medium was endlessly patient, unemotional and more flexible.

Learning with the computer

Where the first type of application has disappeared almost completely, the second type is sometimes still used for learning skills that either do not ask for deep understanding or to automate a given skill.

With the increased performance capabilities of computers, their larger storage capacity, and increasing multimedia and communication possibilities, new educational applications have become possible. At the same time, new insights in the functioning of the human brain, and the structure of human memory have oriented learning psychology and the corresponding instructional design theories towards new insights on how learning takes place, and what the influential factors in this process are (see LeHo's KEFs).

Both simple and complex simulations (including 3D and virtual reality) allow students to test assumptions or look for similarities and correlations to help them understand new theories, for example in natural sciences.

Complex courseware can accommodate the learner's characteristics including prior knowledge, reasoning skills, maturity, learning preferences, etc. In other words it can individualise, personalise and customise the instruction.

Offline and online communication with teachers and peers also add collaboration and social dimensions to the courseware.

Computer peripherals enable computers to be used by children with disabilities and mobile devices allow the storage of large quantities of information and applications on small devices, as well as continual access (as long as a connection is available).

Consumer productivity tools (text and music writing processors, spreadsheets, database programmes, presentation tools, graphics programmes, tools for the production and editing of audio, video, animation, design, publishing, etc.), social media and conferencing software, and whichever additional tools may be developed in future have all extended the potential of ICT to enable learning with the computer and even by computer, in an educational setting.





Finally, school management and administration have also been aided by the use of ICT-based tools. They add flexibility and accessibility to archiving, they provide information and collaboration facilities for staff, as well as monitoring and evaluation of processes.

The potential for ICT seems endless. But there is a caveat. Technologies can, and should be used to support didactics and pedagogy, however, education is much more than just the technology. Technology should NEVER determine what and how a student should learn, nor should it define the learner's personal development.





ICT for children with medical needs: Lessons from the LeHo toolkit and training actions

In the LeHo toolkit and training actions, the LeHo partners have created a collection of materials that they either use themselves or consider valuable for ICT-supported education of children with medical needs, and for the training of their staff (teachers and others). To illustrate innovative and good practices in this use of ICT, some examples of the various types of use are briefly described below. More examples and an extensive description, including references can be found in the LeHo toolkit.¹⁴

While reading the examples in this section, ask yourself the following questions:

- 1. Do I need (this) technology to reach my goals? Why and what for? Think about the KEFs to build up your arguments.
- 2. Am I skilled enough to apply this technology and do I also have the necessary knowledge or available support to help my pupils or students when they need help?

ICT support for teaching

ICT support for teaching can take various formats. There are two main types of materials: instructional materials and tools for teachers (and teaching assistants), and materials and tools for learners. In most cases these products are published in the native language of the users and are adapted to the curricula of the local educational systems. Often they can only be consulted by registered users and reside in separate sections of the same website for teachers and students, along with suggestions for their use.

Commercial companies (usually for a fee) as well as educational authorities (usually for free) offer such materials and tools in many European countries. Most local teacher organisations help their members to find and evaluate these materials.

Materials and tools for teachers

1. On some websites for teachers there is information for continuous vocational training, which contains theory-oriented information to update them on recent developments in learning





psychology, pedagogy and didactics, or background information that they might find useful to help them in their job.

- The Dutch Ziezon website (http://www.ziezon.nl) is an example. It contains a section (also in English), that supports teachers who find themselves working with pupils with medical needs.
- The Italian *Portale Scuola in Ospedale* (http://pso.istruzione.it/; hyperlink tool) has a resources section ("materiali") containing both continuous vocational training courses and educational materials (but is only available in Italian).
- A number of websites in various countries provide teachers with examples of good practice, with complete lessons or lesson items and exercises, or with how-to instructions on the use of ICT tools.
 - Animated presentations and videos (hyperlink.tool). Although not developed with a specific educational objective and/or specific type of learning in mind, animation can be a powerful tool for HHE teachers to present instructional and educational elements in an attractive way. In the LeHo toolkit reference is made to examples of this educational use.
 - **Creating an educational film** (<a href="https://example.com/hyperlink
 - The **SAVEH project** website (in Spanish) (http://www.saveh.es/) contains courses and course elements ("Biblioteca") as well as educational games ("Juegos") that are specifically collected for HHE use.
 - **KlasCement** (http://www.klascement.be/) is a Flemish website (in Dutch) that was specifically developed for teachers to find and exchange educational materials (course elements) for their pupils and students. Currently it contains over 43000 items, covering materials for all school subjects and for learners of all ages, and has over 97000 users.

Materials and tools for pupils and students

- Websites that support learners with online lessons, lesson items and exercises being used more
 extensively at all educational levels. Children with medical needs can, and should use these
 during their time in HHE, especially if they have already used them in their mainstream school.
 This will help them bridge the gap without needing to become familiar with new interfaces,
 different concepts and methods of instruction, or with references to unfamiliar prior
 knowledge.
 - Web-based training (<u>hyperlink tool</u>) contains 225 online exercises on German grammar and vocabulary, along with tests, crossword puzzles and comprehensive reading, and supports the acquisition of German as a foreign language.
 - Bingel (http://www.bingel.be) is a Flemish website (in Dutch), developed by one the most well-known editors of textbooks and learning materials in Flanders. It is used by 80% of primary schools in Flanders and provides learning and exercise materials for various subjects. It can be used during classes as well as at home, and is accessed





with a login procedure, which automatically restricts the pupils' use to pages that are controlled by their teachers. The teachers can either put their own materials on it, or choose from the 4000+ items on the editor's database. The progress of every pupil is measured and results are available for the teacher, pupil and the pupil's parents to see.

- 2. ICT can also support distance education and learning.
 - **Electronic Bags** (<a href="https://example.com/hyperlink.com/hyperlin
 - A more sophisticated solution is the combination of Blackboard pictures and podcasts (hyperlink tool) Pictures taken from the mainstream school classroom are sent along with a podcasts (programs of music or chat that is made available in digital format for automatic download over the Internet) to the child staying in hospital or at home during their illness.
 - Dedicated devices to connect the learner's mainstream school classroom with the hospital
 or home of the learner combine the use of computers, cameras and microphones in a single
 format set up in the classroom. An example of such device is *WebChair* (hyperlink tool).
 - Web-individualschule (hyperlink tool) is a German telepresence service that contains lessons taught by a personal teacher using Skype and is specifically for children that are staying in hospital. Sometimes the constraints of their hospital treatment and often the psychiatric nature of the medical condition may hinder some types of education, leaving this type of ICT use as the only solution possible.
- 3. An inventive application of ICT is the use of robotics in the educational context of a hospital school.
 - Educational Robotics (hyperlink tool) are used to motivate learners and support the
 acquisition of deeper insights in connected subjects (e.g., maths,
 science and technology, and logic reasoning) of the curriculum
 through a constructionist methodological approach to learning.

(Image: http://pso.istruzione.it/index.php/robot-realizzati-dai-bambini-in-ospedale

ICT support or communication

Probably the most influential effect of ICT on modern life is the element of communication it offers. Communication was the key to globalisation and to the explosive development of science and technology today. In HHE, communication technologies can be used to combat isolation of learners with medical needs, to support their education by providing tools for learner-teacher interactions, learner-learner interactions, and for collaborative learning.





• Adventura tok tok (hyperlink.co) is a virtual network to promote interaction between children in hospitals. It offers them the possibility to publish and broadcast their own drawings, cartoons, animated

characters and

(Image: http://santosmiguel.me/

"Monkey in my chair", a USA-based help children specifically suffering from with their classmates. The child with the receives the toy Panda which is taken into representative for the ill child. The panda has a backpack, which can be used to hold notes from friends, or work Panda in my seat (hyperlink tool) is based on organisation set up to cancer to stay in touch medical condition

(Image: https://openclipart.org/detail/89233/chairpanda

school and acts as a

from teachers, and it is taken regularly to and from the ill child and the school and by the parents.

- Facebook, MSN, Skype and WhatsApp to create an online classroom (hyperlink.tool). Students often use Facebook, MSN, Skype and WhatsApp for social networking. However, the creation of online groups that simulate the classroom are also possible with these products. Such groups can be useful, especially when a classmate is ill to keep them up to date with their classroom activities in general, and not only in terms of study.
- Synchronous collaborative learning via shared screens and conferencing (hyperlink.tool). Sharing a screen and mouse control allows children in isolation to actively collaborate and co-construct products online. Any conference system that allows screen sharing and remote controlling would work.
- **Edmodo** (hyperlink tool). Edmodo is an online educational social networking tool with an interface similar to Facebook. It enables teachers to load questions and tasks and for learners to interact within a safe environment. Learners can access content quickly and easily and interact with it intuitively. It can be used for learners who are home- and school-based. It is very easy for children at home to access homework, teaching materials and quizzes set by their teachers.
- As robots for human communication and support start to become more and more affordable and used more frequently (e.g. in rest and care homes, and in hospitals to dispense medicines), HHE environments should consider the possibility of using them for education. They combine the characteristics of dedicated devices like WebChair with humanlike (and emotional) behaviour of well-designed robots. A *French research project* investigates the potential of robots within HHE using Awabot

(Image: Xavier Caré. Shared under a Creative Commons CC BY-SA-4.0 licence)

(http://www.awabot.com/en/).

robots





ICT support for management of the learning/teaching process

Management support using ICT for learning/teaching processes covers two aspects.

- 1. ICT is used for the storage of pupil data with respect to starting levels and progress (measured through tests), with additional processing of this data at the level of the individual, class and even the school level, and to visualise the data as graphs for easier evaluation of the results. Almost all of the electronic learning environments have this facility today.
 - Pupil e-Referral Form, Passport and Review Materials (see also above). HHE situations require more complete and complex data to be collected. The medical condition and treatment is very influential on the personality, behaviour and consequently also on the school results of the learner, and should be understood by the teaching staff. Conversely, the healing process will be influenced by the school results and by the quality of contact between the ill child and the teaching staff and their peers both in the hospital and their mainstream school. For efficient collection and to update this data, it must be available online and be accessible by everyone who is entitled to view it and to contribute. Naturally, this requires a well-secured environment and responsible users to protect the privacy of the child.
- 2. Tools that help monitor the quality of the educational environment.
 - Quality of student experience scale for HHE (hyperlink toolkit) This online scale has two versions: one for hospital schools and one for home education. It measures three dimensions: (1) maintaining refers to how HHE helps the student keep and maintain active what he/she had before their illness; (2) improving refers to how HHE helps the student improve and keep growing despite their medical condition; (3) overall quality of the student experience refers to the overall perception of the student of his/her school experience.

Use of a Virtual Learning Environment (VLE)

Virtual learning environments – or teaching-learning environments – are an all-in-one experience. The teacher uses software in which full courses or parts of courses (lessons, curriculum extensions, illustrations, simulations, exercises, tests, etc.) can be made with the help of templates (therefore bypassing the need to learn programming) in a wysiwyg (what you see is what you get) mode. Communication tools for posing questions and leaving feedback, and collaboration tools for collaborative learning tasks are included in the software. The environments also often contain production tools that enable animation, video and audio inserts, student tracking to inform the teacher about the dates and time spent on each task, and test results and statistics (with graphic charts) about the individual and class performances. VLEs are also known as Electronic Learning Environments (ELE), Course Management Systems (CMC) or Learning Management Systems (LMS). They exist as commercial off-the-shelf products such as Blackboard or WebCT, they can be open source (mostly free to use and adapt but support is charged for) such as Moodle, or bespoke products (developed by institutions for their own individual needs).





• Smartschool http://www.smartschool.be/ (<a href="http://www.smartschool

SMART SCHOOL over 20 different modules. These are divided into 4 groups (communication, administration, education and

student tracking systems). The combination of these components in one package facilitates cooperation in the school. It comes with many additional apps and ad-ins to extend its functionality and addresses primary and secondary education in Belgium.

Real-time distance education

ICT enables a pupil with a medical condition to be virtually present in their mainstream school classroom from hospital or home. Attending classes helps the ill child to keep up with (the main) subjects and thus combat school retardation; it allows the child to maintain social contact with peers, even in cases of isolation to prevent infection; and it encourages the child to get better, as they are distracted from their illness and instead behave as if they are well.

• Bednet (hyperlink tool). Bednet is a Flemish (in the Dutch speaking part of Belgium) non-



(Image: © Bednet vzw (http://www.bednet.be/)

part of the classroom and can zoom in on the black- or smartboard. The child can even take snapshots of what the teacher writes on the blackboard or smart board. He/she can call for the teacher's attention via a special signal and the system also allows the child to take part in group work. With the printer-scanner, written materials can be exchanged, and the camera and microphone allow chatting with classmates after and in between classes. As important as the

profit organization for children with a long term or chronic illness, that offer their services and equipment free of charge to participating schools. The Bednet system requires a set up at the child's site (hospital or home) of a laptop with a camera, headset and printer-scanner, and at the school site which has a dedicated computer, a high definition camera that can be remotely controlled by the child, microphone, loudspeakers and printerscanner. Through a videoconferencing system and dedicated software, the child can watch the classmates. teacher and their and follow everything that happens in the classroom. He/she can ask questions and communicate with everyone who is present. The classroom camera can be



(Image: © Bednet vzw (http://www.bednet.be/))





technology is, however, there is still the need for the Bednet consultants and staff to support the children, as well as the cooperation of the teachers, parents and tutors throughout the period of use.





Collaboration between HHE entities

The specificity of HHE calls for the exchange of ideas and experiences, and for collaborative working. LeHo was born out of this need. It may be sustainably continued in initiatives that are on the basis of school-to-school communication, or at the level of an organisation of professionals.

- e-twinning (hyperlink tool). Launched in 2005 as the main action of the European Commission's e-Learning programme, eTwinning has been firmly integrated in Erasmus+, the European programme for education, training, youth and sport, since 2014. European Schoolnet, an international partnership of 30 European Ministries of Education to develop learning for schools, teachers and pupils across Europe, operates its Central Support Service.
- **HOPE** (Hospital Organisation of Pedagogues in Europe) is an association of European hospital teachers who work in hospital and at home with ill children. Through school and education activities it tries to provide ill children with a positive environment, and with the opportunity to continue with their education, no matter what the illness is. http://www.hospitalteachers.eu/

Money, money makes the world go round: Funding support for HHE

Although ICT is no longer exclusively for a fortunate few, it remains costly. The rapid pace of new developments necessitates the frequent renewal of equipment and software, something welcomed and manipulated by the industries that benefit from constant new releases and updates which must be paid for. Hospital schools in particular, with their relatively small pupil numbers, may find it difficult to secure the necessary funds, whereas mainstream schools can possibly raise more funds through charity events or find sponsors in local service clubs or companies, but hospital schools must rely on subsidies. Participation in projects, either regionally, nationally or European funded projects can help, but these remain a temporary solution. Hence the necessity to collaborate with other schools and the need to share costs and benefits. This type of collaboration also leads to increased numbers of institutions and people who are aware of the issues, which is advantageous for lobbying in the political environment. This also happens to be one of the main objectives of the LeHo project; it must conclude with a document that is suitable to address future education policy makers





Conclusions

What has been described in this Guide is proof of the complexity underlying HHE. Working in such an environment is challenging, as each learner confronts the teacher with a unique situation and particular problems that need to be solved, more so than in mainstream schools. Many teachers will not have encountered any of these issues during their training or in their previous years of teaching outside of the HHE environment. An obvious important factor is the medical condition and its impact on the personality and learning characteristics of the child. But being confronted with illness and perhaps even the eventual death of your pupil will affect teachers emotionally and force them into a personal involvement that goes beyond professionalism.

In this Guide, we have aimed to introduce these aspects of HHE in the context of everyday teaching outside of HHE. As it stands, this is only an introduction. There is much more to learning, 21st century pedagogy and didactics, and in this rapidly changing environment, it is wise for teachers to undertake continued vocational education.

For those who want more in-depth information about some of the aspects introduced here, the well-documented UNESCO Working Papers "The futures of Learning 1, 2 and 3" ¹⁵ contain additional insights and vision. As these publications were not specifically written for the HHE environment, not all the information they contain maybe applicable, however, critical reading may reveal a rich source of information and suggestions that can help teachers to tackle the challenges of their role.

The LeHo partners hope that this Guide has in some way, contributed to renewing and maintaining the teachers' enthusiasm for their demanding roles.





References

- ¹ More information on http://edutechwiki.unige.ch/en/Advance Organizer. Retrieved 2016
- United Nations (1950) Universal Declaration of Human Rights Adopted and Proclaimed by the General Assembly of the United Nations on the Tenth Day of December 1948, Final Authorized Text. New York, United Nations. Retrieved 2016 from http://www.un.org/en/universal-declaration-human-rights/
- ³ UNICEF (2007). A Human Rights-Based Approach to Education for All. New York, United Nation Children's Fund. Paris, United nations Educational, Scientific and Cultural Organization. Retrieved 2016 from
 - http://www.unicef.org/publications/files/A_Human_Rights_Based_Approach_to_Education_for_All.pdf
- UNESCO (2001). Understanding and Responding to Children's Needs in Inclusive Classrooms. A Guide for Teachers. Paris, Inclusive Education Division of Basic Education. http://unesdoc.unesco.org/images/0012/001243/124394e.pdf
- More elaborated information on this topic can be found in LeHo project (2016). The institutional environments of Home and Hospital Education (HHE) in Europe.

 http://www.lehoproject.eu/jdownloads/Public/International%20community/LeHo Institutional environments of HHE in Europe June 2015.pdf
- Ronald McDonald House Charities. (n.d.) What about School. Retrieved 2016 from https://learningprogram.rmhc.org.au/docs/WASBookInteractivePDF.pdf
- Dixon S. (2014). Smithdon High School Policy On Pupils With Medical Needs. Retrieved 2016 from http://www.smithdon.norfolk.sch.uk/media/Policies/Pupils_with_Medical_Needs_Policy.pdf
- ⁸ Children's Hospital School. University Hospitals of Leicester (2015). Pupil Referral Form, Passport and Review Materials. LeHo project http://www.lehoproject.eu/en/toolkit/102-the-pupil-passport
- see e.g.
 - https://en.wikipedia.org/wiki/Learning_theory_%28education%29 Retrieved 2016 http://www.lifecircles-inc.com/Learningtheories/learningmap.html Retrieved 2016 http://www.learning-theories.com/ Retrieved 2016
- LeHo project Capurso, M. & DENNIS, J. (2015). The Key Educational Factors for the education of children with medical needs.
 - http://www.lehoproject.eu/jdownloads/Public/International%20community/LeHo_-Key educational factors for the education of children with medical needs.pdf
- LeHo project Capurso, M. & Dennis, J. (2015). Focus Groups. ICTs and Education of Children with medical needs. final public report.
 - http://www.lehoproject.eu/jdownloads/Public/International%20community/LeHo Focus Groups Final Public Report June 2015.pdf
- ¹² Coffey, H., Cooperative learning. LEARN NC. Retrieved 2016 from http://www.learnnc.org/lp/pages/4653
- Mourik, O.H. (2008). Professional Profile For Hospital Teachers. Den Haag, ZIEZON.
- ¹⁴ LeHo Toolkit (2016). http://www.lehoproject.eu/en/toolkit
- ¹⁵ UNESCO (2015). The Futures of Learning 1: Why Must Learning Content and Methods Change in The 21st Century? Retrieved 2016 from http://unesdoc.unesco.org/images/0023/002348/234807e.pdf
 UNESCO (2015). The Futures of Learning 2: What Kind of Learning for the 21st Century? Retrieved 2016 from http://unesdoc.unesco.org/images/0024/002429/242996e.pdf





UNESCO (2015). The Futures of Learning 3: What Kind of Pedagogies for The 21st Century? Retrieved (2016) from http://unesdoc.unesco.org/images/0024/002431/243126e.pdf