

Patient and family education: from theory to practice

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Patient education – the words

Communication: It can be seen as a process by which messages are exchanged between individuals through a common system of symbols or behaviors.

The message may be a question, a thought or feeling.

The process is successful when the message is transmitted, received and understood effectively . (Anderson 1990).

Information: to update, provide news, to give or impart knowledge of a fact or circumstance

Education: Education is a more complex practice that involves a diagnosis, the choice of learning objectives and the application of teaching techniques and relevant assessment to enable the patients to: know their disease, competently manage therapy, prevent avoidable complications.



World Health Organization

Therapeutic Patient Education

Continuing Education Programmes
for Health Care Providers
in the Field of
Prevention of Chronic Diseases

Report of a WHO Working Group

Therapeutic Patient Education (TPE)

enables people with chronic diseases to manage their illness and

yields benefits in both **health** and **financial** terms.

Many health care providers, however, **lack the skills**

to provide their patients with such an education.



The Regional Office therefore convened a working group to prepare a document specifying the content of programmes for teaching health care providers to provide TPE.

The **Working Group** comprised doctors, nurses, other health care providers and educators from countries throughout the European Region.

to prepare a document indicating the content of a specific education programme for health care providers ... in the field of prevention of Chronic diseases* and therapeutic patient education*. Its aim is:*

*to **help health care providers** acquire the competencies to help patients to self-manage their chronic disease.*

World Health Organization

The WHO European Region has almost

five million nurses

they constitute the largest health care provider group.
Their actual and potential contribution to the management
of chronic disease
is under-acknowledged and under-used

The status of therapeutic patient education in the treatment of chronic diseases

In health care practice outside the hospital,
about **80%** of the diseases treated are **chronic**.

Many patients do not comply with instructions;
fewer than **50%** follow their treatment correctly.

It has been observed that patients are
inadequately informed
about their condition and that few have been helped to
manage or take responsibility for their treatment

The status of therapeutic patient education in the treatment of chronic diseases

Though most physicians are highly competent in diagnosis and treatment, too **few educate** their patients to manage their condition.

There may be several reasons for failing to educate patients, such as too **little time** or lack of awareness of the need to do so.

One reason is that the initial training of most health care, especially medical-care, providers is based principally on **diagnosis** and selection of a therapeutic regimen.

The status of TPE in the treatment of chronic diseases

Though acutely ill patients may benefit from therapeutic patient education, it appears to be an essential part of treatment of long-term diseases and conditions, such as those listed below:

Allergies

Cancers (and sequelae)

Cancer (all sites)

Stomas (laryngotomy, gastroenterostomy)

Blood Haemophilia Thalassaemias

Circulatory system

Arterial hypertensive disease Cardiac insufficiency Cerebrovascular disease (stroke)

Claudication

Ischaemic heart disease, angina

Rheumatic heart disease

The status of TPE in the treatment of chronic diseases

Digestive system

Cirrhosis
Colitis
Crohn's disease
Gastroduodenal ulcer
Malabsorption

Endocrine, nutritional and metabolic disorders

Addison's disease
Diabetes mellitus
Obesity
Thyroid gland dysfunction

Infections

HIV/AIDS
Poliomyelitis (sequelae)
Tuberculosis

Mental and behavioural disorders

Alcohol, drugs, tobacco
and other substance abuse
Alzheimer's disease and Dementia
Depression

Musculoskeletal system and connective tissues

Arthritis and allied conditions
Fibromyalgia
Limb amputation, fractures, burns)
Neck and back disorders
Osteoarthritis
Osteoporosis
Rheumatoid arthritis

The status of TPE in the treatment of chronic diseases

Nervous system

Epilepsy

Hearing loss, deafness

Multiple sclerosis

Paraplegia, tetraplegia and other traumatic brain injuries

Parkinson's disease

Visual disability, blindness

Respiratory system

Bronchial asthma

Chronic obstructive pulmonary disease

Cystic fibrosis

The status of TPE in the treatment of chronic diseases

Different **types of TPE** have been introduced in various health care settings but they have often been arbitrarily designed and poorly taught.

There is an **obvious need** for better- quality educational programmes with a therapeutic intent.

Often patients begin to cope with their disease on their own, but health care providers should use therapeutic patient education to make their
patients' efforts more productive.

The concept of TPE

Health care providers tend to talk to patients about their disease rather than **train them** in the daily **management** of their condition.

TPE is designed therefore to train patients in the skills of **self-managing** or adapting treatment to their particular chronic disease, and in coping processes and skills.



It should also contribute to **reducing the cost** of long-term care to patients and to society.



Target groups

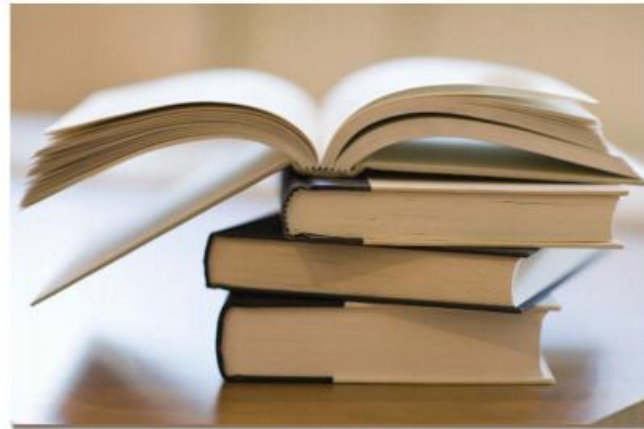
Educational programmes should be **tailored** to the different types of health care provider engaged to various degrees in the care of patients with chronic diseases

These are mainly physicians, nurses, dieticians, pharmacists, physiotherapists, ergotherapists, psychiatrists/ psychologists, social workers, occupational health specialists, and chiropodists.

Other professional categories should be informed about and take part in therapeutic patient education. They include specialists in education, health insurance specialists, hospital administrators, school health educators and others.

HOPE - European Hospital and Healthcare Federation

A clinical and managerial challenge



Self-management and patients' **empowerment** generally are an integral part of the treatment for patients with chronic diseases.

Self-management promotion is often a task of **multi-professional teams**, operating within DMPs (Digital Media Project) or integrated model of care,

which are demanded to give patients and their families the right instruments **to manage the disease**.

The spreading of chronic conditions among the population and the evolutions in management of chronic diseases have had impacts on the **skills** and the **organization** of the work of healthcare professionals.

In particular, the increasing importance of primary care has been requiring **nurses** to take off some tasks and responsibilities previously reserved to doctors and physicians. .

Joint Commission International (JCI) identifies, measures, and shares best practices in quality and patient safety with the world.

JCI provide leadership and innovative solutions to help health care organizations across all settings improve performance and outcomes.

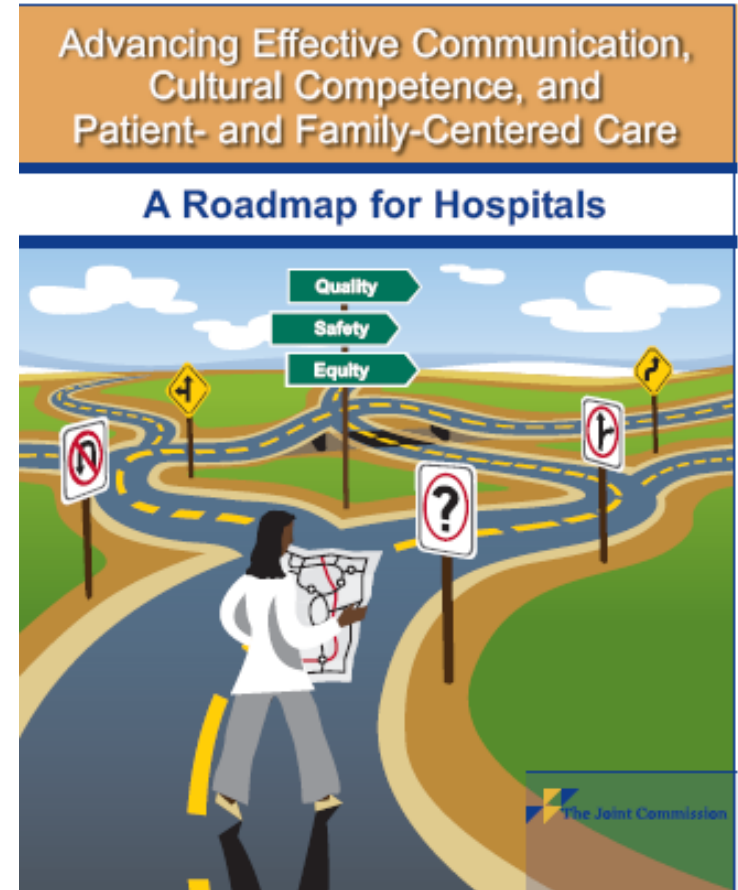
Their expert team works with hospitals and other health care organizations, health systems, government ministries, public health agencies, academic institutions, and businesses to achieve peak performance in patient care

Joint Commission International: Road Map for Hospital

***Effective Communication,
Cultural competence
Patient/Family centred care***

“Continuum of care”

- ***Admission***
- ***Assessment***
- ***Treatment***
- ***End-of-Life Care***
- ***Discharge and Transfer***
- ***Organization Readiness***



Joint Commission International: Road Map for Hospital

A hospital must embed effective communication, cultural competence, and patient- and family-centered care practices into the core activities of its system of care delivery—not considering them stand-alone initiatives—to truly meet the **needs of the patients, families, and communities served.**

The recommendations in the Roadmap for Hospitals do not encompass every aspect of these three areas, but they do represent key issues that hospitals should consider to meet the **unique needs** of each patient.

Joint Commission International



Patient and Family Education (PFE)

Standard PFE.1

The hospital provides education that supports patient and family participation in care decisions and care processes.

Intent of PFE.1

Hospitals educate patients and families so that they have the knowledge and skills to participate in the patient care processes and care decisions. Each hospital builds education into care processes based on its mission, services provided, and patient population. Education is planned to ensure that every patient is offered the education he or she requires. The hospital chooses how it organizes its educational resources in an efficient and effective manner. Thus, the hospital may choose to appoint an education coordinator or education committee, create an education service, or simply work with all staff to provide education in a coordinated manner.

Objective

**To know - Share – Acquire
Appropriate skills**

Back home

Self- confidence Self- management

Satisfying social life



Educational Recorder

Literature Research

PubMed

Limits: Humans, Meta-Analysis, Review, English, Cancer, Systematic Reviews, All
Child: 0-18 years

Key words : Therapeutic patient education, education, empowerment, self care,
oncology service, hospital , outpatient, blood marrow transplantation. bone marrow
transplantation.

Journals, Websites

www.etp-journal.org

“Patient Education and Counseling Journal

www.journals.elsevierhealth.com/periodicals/pec

Annual Congresses **TPE**

EBMT

Therapeutic patient education

It is an activity aimed at helping the patient and his family to

Understand the nature of the disease and treatments

Collaborate actively throughout the course of treatment

Take care of their health

to maintain and improve their **quality of life**

TPE must be managed by health workers

Trained to instruct the patient and / or his/her family members
to manage their disease and thus
to prevent avoidable complications

TPE is a complex practice that involves :

Educational diagnosis

learning objectives

techniques for teaching
and assessment

To allow the patients to :

Know their illness;

Manage competently their therapy and lives (self-management);

Prevent avoidable complications

"educational continuum" divided into three phases:

- ❖ **Initial Education**
- ❖ **Educational Follow-up**
- ❖ **Educational resumption**

- ❖ **Educational diagnosis**
- ❖ **Educational contract**
- ❖ **Assessment** of skills to be acquired
methods and techniques to be adopted
- ❖ Evaluation of **results**

Existing Material

Educational Form

Unità Operativa _____ Foglio n. _____
SCHEDA PER LA RILEVAZIONE DEL PROGRAMMA EDUCATIVO
 Cognome _____ Nome _____
 Data del ricovero _____ 1° Ricovero ☐ Follow-up ☐

Espresso
 Nome
 Cognome
 Data di nascita

	NO	SI (Specificare codice)
Eventuali barriere all'apprendimento		

	Paziente	Genitori	Altro (specificare)
Destinatari del programma			

Informazioni fornite	METODO INSEGNAMENTO				CODICE DI VALUTAZIONE			
	Data:		Data:		Data:		Data:	
	Medico	Infermiere	Medico	Infermiere	Medico	Infermiere	Medico	Infermiere
Malattia di base, condizioni di salute								
Partecipazione alle decisioni relative alle cure								
Uso sicuro ed efficace dei farmaci/presidi/apparecchiature mediche								
Aspetti nutrizionali e dieta								
Prevenzioni delle infezioni e norme di profilassi igienico-comportamentali								
Eventuale riabilitazione da seguire								
Gestione del dolore								

Firma infermiera e/o medico secondo competenza

Codice barriera all'apprendimento	Modo di insegnamento	Codici di valutazione
1. Limiti cognitivi	1. Istruzioni verbali	1. Educazione completata: ripete le informazioni ricevute e/o esegue una dimostrazione pratica
2. Barriere emotive	2. Dimostrazioni pratiche	2. Necessita di ulteriori istruzioni
3. Barriere linguistiche	3. Opuscolo/altro materiale cartaceo	3. Necessita di ulteriori informazioni
4. Condizioni fisiche	4. Materiale inviato via mail	4. Non in grado di ricordare le informazioni ricevute o di eseguire una dimostrazione pratica
5. Barriere religiose, culturali, etiche	5. Telefonata	
6. Problemi visivi	6. Audiovisivo	
7. Problemi uditivi		

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Existing Material

Unità Operativa Ematologia ed Oncologia Pediatrica
Trapianto di cellule staminali emopoietiche

Sig.ra	_____
Nome	_____
Cognome	_____
Via di casa	_____

CARTELLA EDUCATIVA Di _____

- E' stato effettuato il primo colloquio con il paziente/famiglia in data _____
Eventuali problematiche riscontrate _____

- Eventuali barriere dell'apprendimento (lingua, cultura, religione, stato sociale, giovane età, scolarità): _____

- Sono state spiegate le norme comportamentali per l'ingresso nel reparto di degenza TCSE.
Data _____ Firma _____

- Sono state spiegate le norme igieniche, personali e ambientali, da osservare in reparto.
Data _____ Firma _____

- E' stato consegnato il libretto esplicativo circa "il trapianto di cellule staminali emopoietiche in pediatria".
Data _____ Firma _____

[illegible][illegible][illegible]

Key Issues	Eligibility of patients	Direct Admission in HSCT	No foreign pts
	Nursing management only	Only allogeneic HSCT	

Guide for completing the form

**no opportunities for sharing the project with the staff
no training or specific information**

Proposal of a new Record

Etichetta
anagrafica

Cartella educativa
Primo colloquio e prima raccolta dati
Dati anagrafici

Cognome _____ Nome _____
Data Di Nascita _____ Indirizzo _____
Città _____ Nazione _____

Stato attuale

Residente _____
Necessità di abitazione si no Necessità aiuto assistenza sociale si no
Necessità mediazione culturale si no

Condizione scolastica (attuale o precedente) _____
Progetti per il futuro _____
Cambiamenti scolastici _____
professionali _____

Modalità di apprendimento preferita _____
Abitudini di vita _____ e dei genitori _____
sport /Hobby praticati _____
Rete relazionale (famiglia, amici, ...) _____
Mantieni i contatti, se sì in che modo _____

Aspirazioni affettive _____

Atteggiamenti del paziente durante primo incontro

Ha avuto educazione sanitaria specifica precedente (approfondimento con le schede specifiche)

Rapporto con la malattia _____

Cosa pensa del Trapianto _____

Autonomia nella medicazione (se presente) si no altro _____
o assunzione farmaci si no altro _____

Si presenta: tranquillo __, collaborante __,
ansioso __, angosciato __, preoccupato __, arrabbiato __.

Passivo - rassegnazione _____

Attivo - dinamismo _____

Autonomia - dipendenza rispetto agli accompagnatori:

Completamente autonomo 1 2 3 4 5 6 completamente dipendente

Barriere oggettive all'apprendimento:

Limiti cognitivi __, età __, scolarità __, stato sociale __, cultura __, religione __, lingua __,
emozione __,
condizioni fisiche __, visive __, uditive __, altro _____

Caregivers principali

Grado di parentela: _____ Cognome _____ Nome _____
Data Di Nascita _____ Luogo _____ Stato _____
Scolarità _____ Professione _____ Tel. _____
Disponibile all'apprendimento: si no Barriere _____
Si presenta: tranquillo __, collaborante __, ansioso __, angosciato __, preoccupato __, arrabbiato __

Grado di parentela: _____ Cognome _____ Nome _____
Data Di Nascita _____ Luogo _____ Stato _____
Scolarità _____ Professione _____ Tel. _____
Disponibile all'apprendimento: si no Barriere _____
Si presenta: tranquillo __, collaborante __, ansioso __, angosciato __, preoccupato __, arrabbiato __

Grado di parentela: _____ Cognome _____ Nome _____
Data Di Nascita _____ Luogo _____ Stato _____
Scolarità _____ Professione _____ Tel. _____
Disponibile all'apprendimento: si no Barriere _____
Si presenta: tranquillo __, collaborante __, ansioso __, angosciato __, preoccupato __, arrabbiato __

LEGENDA

Codice compilatore	Metodo di valutazione:	Livello di apprendimento:	
1. medico	-Comprensione verbalizzata	-Raggiunto	R
2. infermiere	Domande/risposte	-Parzialmente raggiunto *	PR
3. psicologo	Carte di Barrow	Non raggiunto *	NR
4. fisioterapista	-Abilità dimostrata	* Necessità di ripetizione	
5. _____	-Altro (specificare)	- non è in grado di ricordare	
6. _____	-questionario	informazioni o eseguire l'azione	NP
		(non possibile)	
Modalità educativa:	Ambito/ obiettivo educativo:	Destinatario:	Codice barriera all'apprendimento:
Istruzioni verbali	IV	Paziente	PZ
Dimostrazione pratica	D	Madre	M
Materiale	competenze intellettuali	Padre	P
cartaceo/opuscolo	M	gestuali	CG
inviato via email	E	relazionali	CR
Telefonata	T		
Audiovisivo	A		
			1-Limiti cognitivi
			2-Barriere emotive
			3-Barriere linguistiche
			4-Condizioni fisiche
			5-Problemi visivi
			6-Problemi uditivi
			7-Barriere religiose, culturali, etiche

Scheda 1: rilevazione conoscenze igiene

	Compilatore	Metodo o veicolo usato	Acquisito		Livello o grado	Bisogno educativo	Competenza generale	Integrazione sociale	Ambito Medicinali Intervento	Destinatari	Prossima valutazione	Sanzioni e considerazioni
Importanza igiene	Codice Firma	data	si	no		Significativa igiene	Singoli protocolli	Igiene comunità			firma	
Lavaggio mani	Codice Firma	data				protocollo	Corretta esecuzione	In ambienti comuni			firma	
Igiene personale	Codice Firma	data				Protocollo ispezione del corpo	Corretta esecuzione				firma	
Igiene intima	Codice Firma	data				Protocollo o, corretta valutazione	Corretta esecuzione				firma	
Igiene orale	Codice Firma	data				Protocollo o specifico	Corretta esecuzione				firma	
Igiene capelli	Codice Firma	data				Modalità corretta	Corrette sequenze				firma	
Cambio indumenti biancheria	Codice Firma	data				Procedura interna	Corretta esecuzione				firma	
Cambio biancheria letto	Codice Firma	data				Procedura aziendale	Corretta esecuzione				firma	
Igiene pulizia stanza	Codice Firma	data				Attenzione i particolari					firma	
Igiene pulizia bagno	Codice Firma	data				Attenzione i particolari					firma	
Animali domestici	Codice Firma	data									firma	
Norme igieniche a casa	Codice Firma	data									firma	
Norme igieniche fuori casa	Codice Firma	data									firma	

- Interviews / information material
- Competence check forms
 - HSCT process
 - hygiene
 - preventing infections
 - nutrition / hydration
 - Elimination
 - Vital signs
 - Therapy
 - Central venous Catheter(CVC)
 - Mobilization or other
- skills required at discharge
- Educational Follow up

Forms

Scheda 8: rilevazione conoscenza CVC

	Compilatore	Metodo valutazione	acquisito		Livello Apprendimento	Competenza			Ambito Modalità Intervento	Destinatari	Prossima valutazione	Barriere e considerazioni
			si	no		intellettuale	gestuale	sociale				
Necessità CVC	Codice _____ Firma _____	_____	Data _____	_____	_____	Info su terapie, chemioth. trapianto	_____	_____	_____	_____	firma _____	_____
Quale CVC	Codice _____ Firma _____	_____	Data _____	_____	_____	differenze anche per età e condizioni	_____	_____	_____	_____	firma _____	_____
Per quanto tempo	Codice _____ Firma _____	_____	Data _____	_____	_____	applicazione permanenza e rimozione	_____	_____	_____	_____	firma _____	_____
Lavaggio mani	Codice _____ Firma _____	_____	Data _____	_____	_____	Procedura per gestione CVC	Corretta esecuzione	_____	_____	_____	firma _____	_____
Medicazione sapere	Codice _____ Firma _____	_____	Data _____	_____	_____	Procedura medicazione	_____	_____	CI M procedura interna	MP	firma _____	_____
Medicazione simulazione	Codice _____ Firma _____	_____	Data _____	_____	_____	Procedura medicazione	Corretta esecuzione su manichino	_____	CG D	MP	firma _____	_____
Medicazione esecuzione	Codice _____ Firma _____	_____	Data _____	_____	_____	Procedura medicazione	Corretta esecuzione su bambino	_____	CG D	MP	firma _____	_____
Medicazione Socialità	Codice _____ Firma _____	_____	Data _____	_____	_____	Sicurezza CVC	Cura ed attenzione al CVC	Situazioni da evitare	CI CR	MP	firma _____	_____
Riconosce into infezioni	Codice _____ Firma _____	_____	Data _____	_____	_____	Valutazione medicazione	_____	_____	_____	_____	firma _____	_____
Riconosce into fuoriuscita	Codice _____ Firma _____	_____	Data _____	_____	_____	Sicurezza CVC	Cura ed attenzione al CVC	_____	_____	_____	firma _____	_____

Four groups

In our team 4 groups are working on:

CVC Management

Oral therapy at home

Hygienic care

Diet

New educational forms have been proposed

And now we are trying them

The whole process must be

Written Registered



Oral Therapy at home

patient _____
label _____

**DIPARTIMENTO DI EMATOLOGIA ED ONCOLOGIA PEDIATRICA
TRAPIANTO DI CELLULE STAMINALI EMOPOIETICHE
Evaluation form for oral therapy at home**

• Do you know the medicines that you will need to take orally at home?

No, Delivered list. date _____ signature _____

Yes, verbal check of knowledge: if / she lists the drugs or reads a list:

Daclon	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
antra	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
Sandimmun	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
Acyclin	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
Cortisone	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
Lasix	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
_____	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
_____	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____
_____	Yes <input type="checkbox"/>	no <input type="checkbox"/>	not applicable <input type="checkbox"/>	notes _____

Notes _____

Signature _____ date _____ To be re-evaluated: no ☐ yes ☐

Oral Therapy at home

- Do you understand the importance of the medications that the patient will take orally at home?

No: Repeat education in date _____ Signature _____ date _____

Yes : verbal check of the knowledge

Bactrim	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
Antra	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
Sandimmun	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
Acyclin	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
Cortisone	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
Lasix	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____
_____	Yes <input type="checkbox"/>	no <input type="checkbox"/>	to reinforce <input type="checkbox"/>	notes _____

note _____

Signature _____ date _____ To be re-evaluated: no ☐ yes ☐

Oral Therapy at home

- **Practical demonstration on dosage and administration. Did you understand all steps?**
No: need more information: What _____
in date _____ Signature _____ date _____
Yes: Verbal check on dosage/dilution/times of administration
Signature _____ date _____ To be re-evaluated: no ☐ yes ☐ _____
- **Practical demonstration on dosage and administration. Did you understand all steps?**
No: need more information: What _____
in date _____ Signature _____ date _____
Yes: Verbal check on dosage/dilution/times of administration
Signature _____ date _____ To be re-evaluated: no ☐ yes ☐ _____
- **Dosage and administration by the patient / caregiver. Are you sure in every steps ?**
No: need more information: What _____
in date _____ Signature _____ date _____
Yes: practical and verbal check on dosage/dilution/times of administration
Signature _____ date _____ To be re-evaluated: no ☐ yes ☐ _____
- **Dosage and administration by the patient / caregiver. Are you sure in every steps ?**
No: need more information: What _____
in date _____ Signature _____ date _____
Yes: practical and verbal check on dosage/dilution/times of administration
Signature _____ date _____ To be re-evaluated: no ☐ yes ☐ _____

Oral Therapy at home

- Did you receive the weekly schedule of the drugs to be administered at home? Is it all clear?

No: need more information: What _____

In date _____ Signature _____ date _____

Yes verbal check on times of administration

Signature _____ date _____ To be re-evaluated : no ☐ yes ☐ _____

- Do you need more information on

_____ given in date _____ signature _____

Signature _____ date _____ To be re-evaluated : no ☐ yes ☐ _____

_____ given in date _____ signature _____

Signature _____ date _____ To be re-evaluated : no ☐ yes ☐ _____

Education for _____

firm caregiver _____

Date discharge /trasfer _____

Signature _____

Oral Therapy at home

Name	DIPARTIMENTO DI EMATOLOGIA ED ONCOLOGIA PEDIATRICA TRAPIANTO DI CELLULE STAMINALI EMOPOIETICHE													
	Home therapy													
	Monday		Tuesday		Wednesday		Thursday		Friday		Saturday		Sunday	
Bactrim 80 mg x 2 sabato											9	21		
cp da 160 mg (trimetoprim) 1/2 cp x 2 sabato														
Antra 40 mg x 1	9		9		9		9		9		9		9	
Omeprazolo (2 cp da 20 mg) x 1														
Tacrolimus	9	21	9	21	9	21	9	21	9	21	9	21	9	21
0,5 mg (1 cp da 0,5mg) x 2														
Aciclin 800 mg x 3	9	16	23	9	16	23	9	16	23	9	16	23	9	16
Aciclovir 1 cp da 800 mg x 3														
Diflucan 200 mg x 1 (fluconazolo)		14		14		14		14		14		14		14
1cp da 200 mg x 1														
Ursacol (acido ursodesossicolico) 450 mg x 2	9	21	9	21	9	21	9	21	9	21	9	21	9	21
1cp da 300 mg + 1cp da 150mg x 2														
cp da 300 mg + 1cp + 1/2 cp x 2														
Medrol 10 mg x 2	9	23	9	23	9	23	9	23	9	23	9	23	9	23
metilprednisolone cp 4 mg (2,5 cp x 2) ose														
metilp cp 16 mg (1/2 cp) + cp 4 mg (1/2cp) x2														
Medrol 12 mg x 1		16		16		16		16		16		16		16
metilprednisolone cp 16 mg (3/4 cp x 1)														
metilprednisolone cp 4 mg (3 cp x 1)														
Delivered on the data _____ Physician signature _____ Nurse signature _____														

Barrows Cards



Immunosuppressive therapy
At home



Food
at home



You have just been discharged from hospital after hematopoietic stem cell transplantation. At home, you are going to continue with the immunosuppressive therapy taking it orally – soft capsules or syrup - instead of intravenously. In your hospital discharge letter, you will find instructions about formulation, doses and timing.

Situation Barrows Card

Barrows Cards

THIS MORNING YOU HAVE
YOUR BLOOD TEST AT THE
DAY HOSPITAL.



"I'LL TAKE MY THERAPY
ANYWAY."

WRONG

Immunosuppressive blood
concentration varies
according to the time of the
last intake. After taking the
medicine, your blood test
would show an unusually
high blood concentration.

Barrows Cards

ORAL SUSPENSION HAS AN
UMPLEASANT TASTE.



"I'LL DILUTE IT WITH SOME
GRAPEFRUIT JUICE."

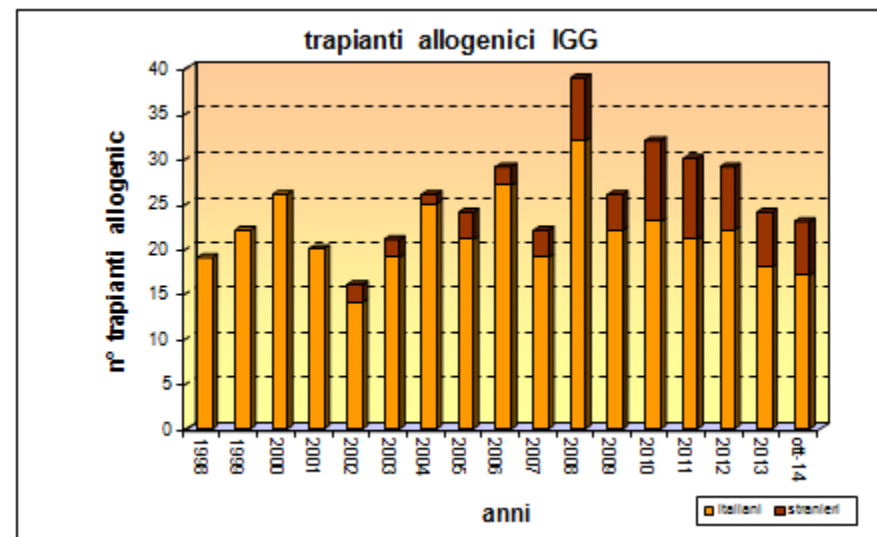
WRONG

Taking the immunosuppressor
in combination with
grapefruit juice increases its
bioavailability because of an
interference of the fruit with
the drug metabolizing enzyme
system.

If you feel like drinking
something you can dilute the
oral solution with any other
juice or
non-alcoholic drink, according
to your taste!

Barrows Cards in the immunosopressive Therapy

Anno	Trapianti allogenici	Pazienti italiani	Pazienti Stranieri	Barrows In italiano	Barrows in Inglesi
2013	18	9	9	12	-
2014	18	11	7	2	2
2015	4			1	



Barrows Cards in the Low Microbial Diet

NUMBER CARD	POWER/ QUALITY RECOMMENDATIONS	SCORE
1	B 3	1
2	B 3	1
3	A 2	3
4	A 3	2
5	A 2	3
6	A 2	3
7	B 3	1
8	A 2	3
9	A 2	3
10	B 3	1
11	B 3	1
12	A 2	3
13	A 3	2
14	A 3	2
15	A 2	3
16	A 3	2

<u>Level of evidence</u>	Value
A 2	3
A 3	2
B 3	1

**validation and creation score card
(pilot test in progress).**

Financial Sustainability :

- no "start-up" cost
- no "per year" cost
- savings per year

Indicators:

- Blood Value Ciclosporin,
- Hospitalization costs
- number of phone calls for the Family's doubts
- Family satisfaction
- satisfaction nurse educator.

The qualitative analysis

results in a

higher satisfaction:

User (adolescent and family)
nurse educator

Fewer:

telephone calls for clarification / problems

No complications at home

no hospitalizations for seizures

A reduction of blood samples for cyclosporine dosage

Next Steps

The study is "in progress":

- To **extend** the educational tool for families.
- **Validate** the "score card" in the use of Barrows card for Low Bacterial Diet.
- Validate the instrument in **English**.
- Validate the tool in **other languages**

The Barrows cards future

Apply the tool in **other settings**

Design and evaluate the tool for therapeutic education with **other objectives**
(managing central venous catheter at home?)

Monitor the contents of telephone triage

General Remarks about TPE

Involvement of whole HCST Team

Identification of a person (s) Responsible for Education

Recognition and transcription of what we do

Educational aspects considered and
written in the existing nursing record

better management of patient discharge

Remarks from child / family

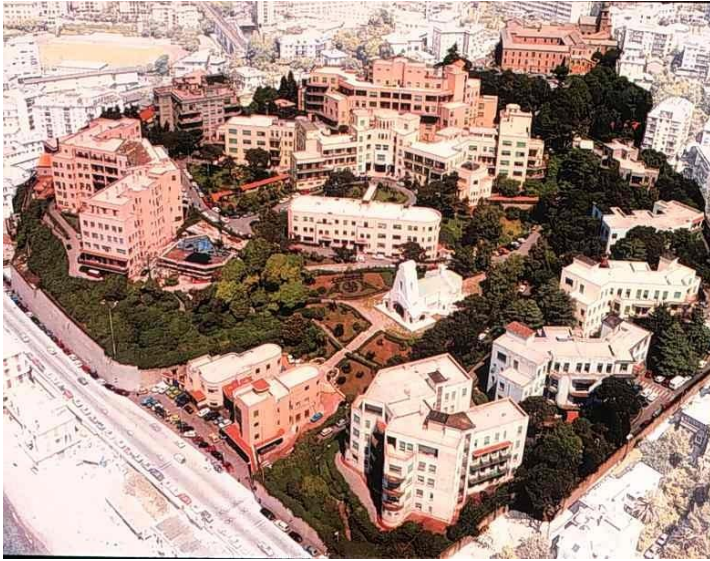
The feedback allows us to keep checking the educational process

Greater confidence

Significant Increase in the number of questions from parents

The evaluation of their progress makes parents more self-confident at the discharge

Thank you



for
your

attention

