THE DRAGOS NURSE PROJECT
A project to pilot and develop a “key specialist nurse” model (“Dragos Nurse”) for children and young adults with cancer in Bucharest, Romania

Hospices of Hope
Re-cap of Background

- Romanian hospitals under-resourced
- Lack of holistic care and co-ordination of services for children with cancer
- Palliative care for hospitalized children non-existent
- Most children with cancer treated in capital Bucharest
- Builds on Hospice Casa Sperantei’s expertise
- Families find it hard to cope
The Team:
Dragos team (currently 3 nurses backed by doctor and social worker) part of Hospice Casa Sperantei team
The role of the Dragos Nurse

- Ensure that the child’s needs are properly assessed
- Ensure that a care plan is established and followed
- Coordinate the care across specialist and local health care, across sectors and geographical boundaries, including all care
- Be a named contact for a young person
- Plan transition care if needed
- Act as an advocate
- Involve parents and other family members
The role of the Dragos Nurse (continued)

- Ensure local practitioners are adequately informed
- Ensure the young patient or carer can recognise an emergency situation
- Coordinate or provide direct clinical care including palliative care
- Refer patients to local specialist services
- Provide specialist palliative care advice to staff
- Provide specialist palliative care to children in their homes (Bucharest only)
Flori Baltag - Team Leader
Flori Baltag - Team Leader
The results so far (first 18 months)

- The Dragos team is now fully trained and operational (5 staff)
- The team works mainly in 3 of the largest Paediatric Hospitals in Bucharest
- 225 children and young people have received care (target of 165)
- Average of 75 family members receiving counselling and support each month
Grandmothers are often the main carers
The results so far (cont.)

- 25 of the patients died during the last year
- 38 were discharged from the hospital and transferred to their local medical institutions
- 21 were transferred to the Home Care service
- All the patients received symptom control, medication, counselling and psycho-emotional support
The results so far (cont.)

- 100 patients received social and material support
  - food
  - help to obtain social rights
  - counselling and support
  - toys, cosmetics (detergents for the Pediatric Oncology Wards)
  - Christmas party (and other recreational activities)
  - Birthday celebrations etc
Patient receiving food at Onclogy Hospital
Christmas party at hospital
Special moments
The results so far (cont. . .)

• Average of 222 communications with other specialist/agencies per month

Other interventions:
  – ICU Support
  – Post surgery preparation
  – Physiotherapy assessment
  – Volunteers were involved in recreational activities with the children
The results so far (cont..)

- More drugs now available in the hospitals
- More than 95% of patients pain controlled after two weeks
- Drug protocols available in hospitals
- Network of palliative care providers published
- 160 hospital staff educated formally and informally
Impact
Princess Sophie visiting patients June 2013
CASE STUDY

Third degree strocytoma - optic nerve
Dragos Nurse Team Leader
Baltag Florentina
Case history

PATIENT V.

• Patient aged 9, twin birth with imminent abortion, birth by c-section, spontaneous term.
• Weight: 2.800 KG
• Patient fed artificially, psychomotor and weight development corresponding to age stages.
Affected with bilateral blindness at 9 months, patient diagnosed in the department of neurosurgery Iasi with bilateral optic nerve glioma.

2009 had a partial resection of the optic nerve tumors

2012 appeared headache and vomiting and the patient was hospitalized in Bagdazar Arsenal Hospital, Bucharest
Case history

-septostomie and ventricular drainage unishunt were made
-partial resection of tumour formation was made

In 2013 was admitted to Onco-pediatric ward of the Institute of Oncology" Professor Doctor Al. Trestioreanu", Bucharest.

Referred to Dragos Team by hospital consultant
Intervention of the Dragos Hospital Team - HOSPICE Casa Sperantei

Starting with the referral of the patient in 2013 until present, the Dragos team’s intervention comprised of:

➢ Identifying the problems and the needs of the patient and his family.
➢ Pain management
➢ Management of other symptoms: nausea, vomiting, constipation
➢ Biological samples were taken from the patient's home
➢ Treatment was administered subcutaneously
Intervention of the Dragos Team

➢ Material Help (diapers, creams and medicines, etc..)
➢ Counselling of the mother on family planning techniques.
➢ Social worker helped to obtain social subsidies
➢ Help with food, toys and sanitary products.
➢ Facilitating a program for siblings afterschool
➢ Integrating patient and siblings in all activities and social events organized by the Hospice Casa Sperantei:
The Intervention of the Dragos Team

➢ Summer Camp, Christmas Party, seaside trips
➢ The patient’s sister was enrolled at a balet school
➢ The patient was transferred by the Dragos Nurse to the Homecare team of Hospice Casa Spetantei Foundation
Christmas Party 2013
Summer Camp 2014
New Bucharest Hospice
Bucharest Hospice

- 8 beds for children
- Intensive palliative care
- Training Centre
- Paediatric Home-care team base
- Sensory room and day centre
- Bereavement counselling
New children’s centre
(Rural area close to Bucharest)
A “home of hope” for children

- Respite Care Centre
- Play therapy and counselling
- Day care centre
- Summer camp venue
- Rehabilitation – activities/workshops
- Interaction with local communities
Key challenges

- High demand for services – more hospitals asking for help
- Lack of qualified staff
- Director of one hospital causing problems
- Lack of drugs and staff in hospitals
- Corruption in State system
- Attitudes still need to change
- Need for palliative care in-patient unit (almost ready)
Key lessons learned

- Prioritising where we can have most impact
- Setting boundaries for caseloads
- Demonstrating good practice and effectiveness of drugs
- Leading by example – a new way of caring
- Education is all important
And finally...

Thank you!

hospicesofhope