

Children's Palliative Home Care Service



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Aim of Palliative Home Care Service

To provide specialized palliative care for children with life-threatening and life-limiting disease in their homes and community

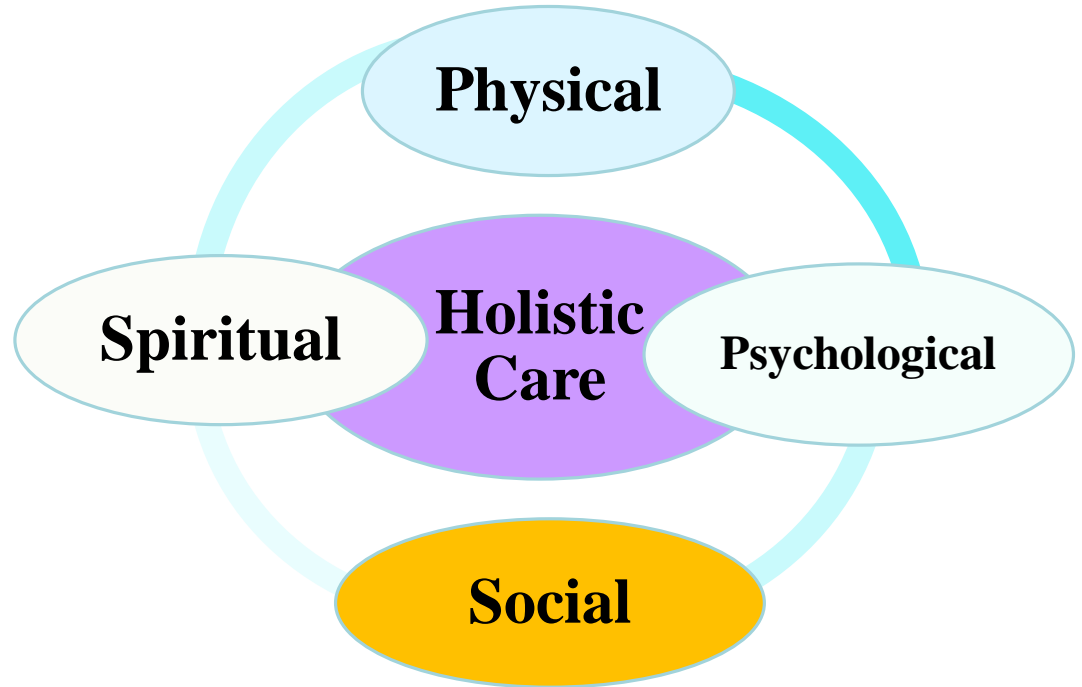


Aim of Palliative Home Care service



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**Enhance
quality of life**



Children's Palliative Care Service is



Child-centred

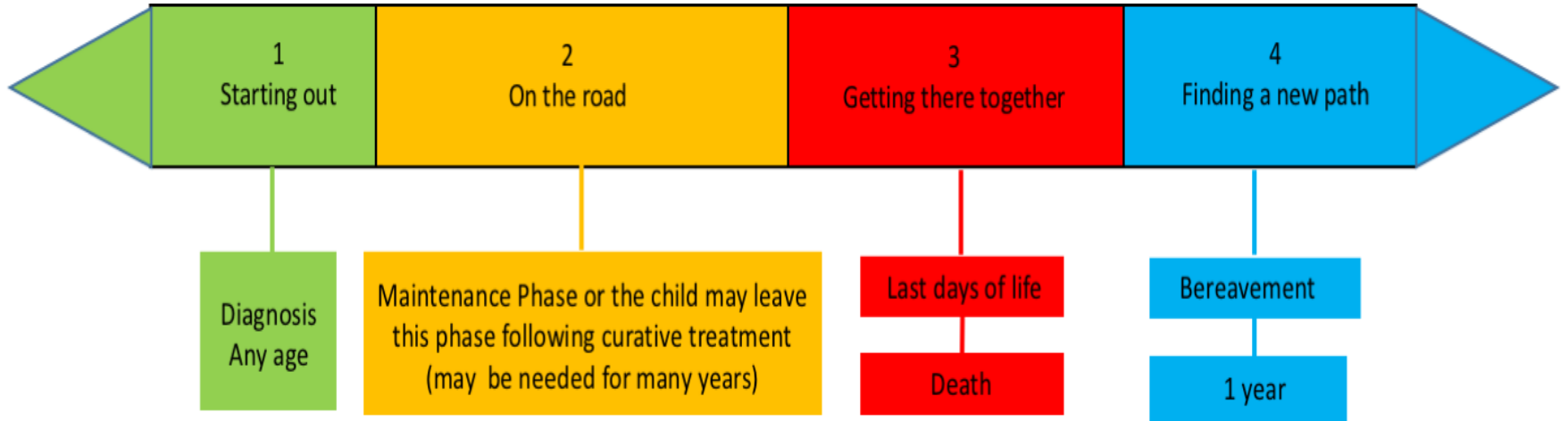


Family-centred

WHEN TO START?



Patient journey

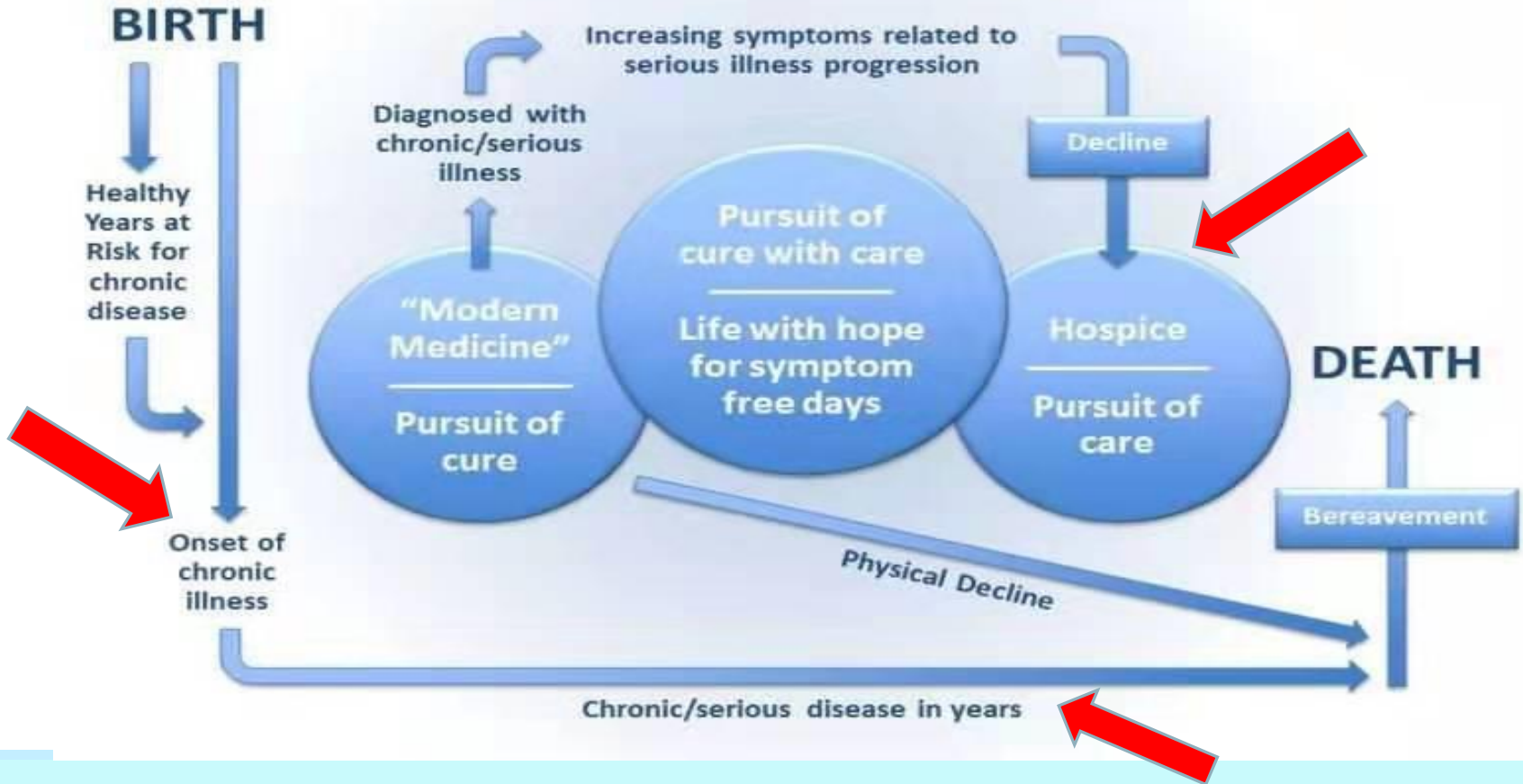


Time for palliative care

- Not only during last stage of disease
- Should start as soon as someone is diagnosed with life limiting illness
- Can be given at any setting such as home, community, hospital

It differs from hospice

SCOPE OF PALLIATIVE CARE



Scope of Palliative Home Care service

Discharge plan

- During admission
- Family meeting: parents, carers, school workers
- Multi-disciplinary approach
- Flexible plan
- Continuous assessment, discussion and evaluation

Plan for discharge I

Assess the physical needs of the child

e.g. nutritional requirements,

line care, turning,

mouth care, skin care,

bathing,

distressing symptom management

Plan for discharge II

Assess the home environment and the equipment needs to support home care

e.g. Commode chair, wheelchair, sitting cushion
oxygen concentrator, suction machine,
Hospital bed, air mattress
PCA machine, oximeter
cardiac monitor

Plan for discharge III

Assess the psychosocial needs of the child and his/her family

♥ understand parents' fears and worries

e.g. What will happen at home?

How can I care for my child at home?

What should I do to make him comfort?

What should I do in emergency?

Plan for discharge IV

♥ Explore the feelings of the child

♥ To help the relatives to accept the child's needs and right to maintain the maximum possible degree of independence

Plan for discharge V

♥ Clear explanation and advice

Care at home, equipment needed,
management during emergency, signs and symptoms,
disease progress and prognosis

♥ Carer training


Use, cleaning, maintenance of equipment
Skills training and return demonstration

Plan for discharge VI

♥ Communication channel

Follow up by Primary team & PPC team, other specialists
24-hour on call, case conference

♥ Step by step & Try home leave

- From hours to days to weeks  long term discharge
- May need escort to increase parents' confidence

Home care support

- Symptom assessment

 - e.g. Pain rating Scales

 - Visual Analog Scales

- Symptom management

 - Common symptoms occur in terminal stage such as pain, fatigue, dyspnoea, nausea and vomiting, constipation, insomnia, anorexia, bleeding, infection

- ♥ Medication administration

 - orally, intravenous, transdermal, PCA, rectally

- ♥ Observation of the effect and side effects of the medication

Home care support

- ♥ Daily care advice
- ♥ Perform nursing procedure at home
- ♥ Skills training and return demonstration
- ♥ Equipment search and usage, maintenance
- ♥ Monitor the disease progress
- ♥ Psychosocial support to patient and family members
- ♥ 24/7/365

Psychological support for family

Good symptom management

Inform disease progress

Adequate explanation and guidance

Listen & answer

Always available

Preparation for die at home I

IF THIS IS THE WISH OF PATIENT AND FAMILY

- ✓ Explore the wish of patient and his/her family members
- ✓ Assess the acceptance of family members including grandparents and siblings
- ✓ Assess the home environment
- ✓ Discuss with the doctor about the arrangement after the death of the child

Preparation for die at home II

It requires:

- ♥ More than one capable carers who can cope with serious illness and take turn to take care of the patient
- ♥ Home care nurses who can provide 24-hour support and can visit when needed
- ♥ An attentive doctor to be communicated
- ♥ A capability by the caring team to respond quickly to new problems
- ♥ A guarantee of rapid inpatient admission in the event of major crisis

Preparation for die at home III

- Explore the concerns of patient and family members
e.g. funeral arrangement
- Advise the family to call home care nurses if they have queries
- Continuous assessment of family wish
- Care of other family members such as siblings
- Keep the attending doctor informed of the child's condition

Preparation for die at home IV

Explain the procedures after the death of child

e.g. What should they do first?

What can they do for the dead body?

Where will the dead body go?

When to call the ambulance?

How to call the ambulance?

Preparation for die at home V

Educate the parents/main carer

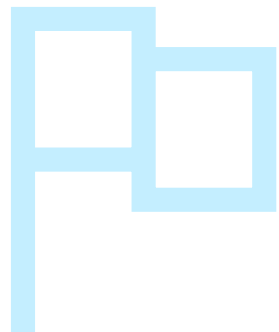
e.g. What the common signs and symptom occur at the terminal stage?

How to know that the patient is in dying process?

What can they do at this stage?

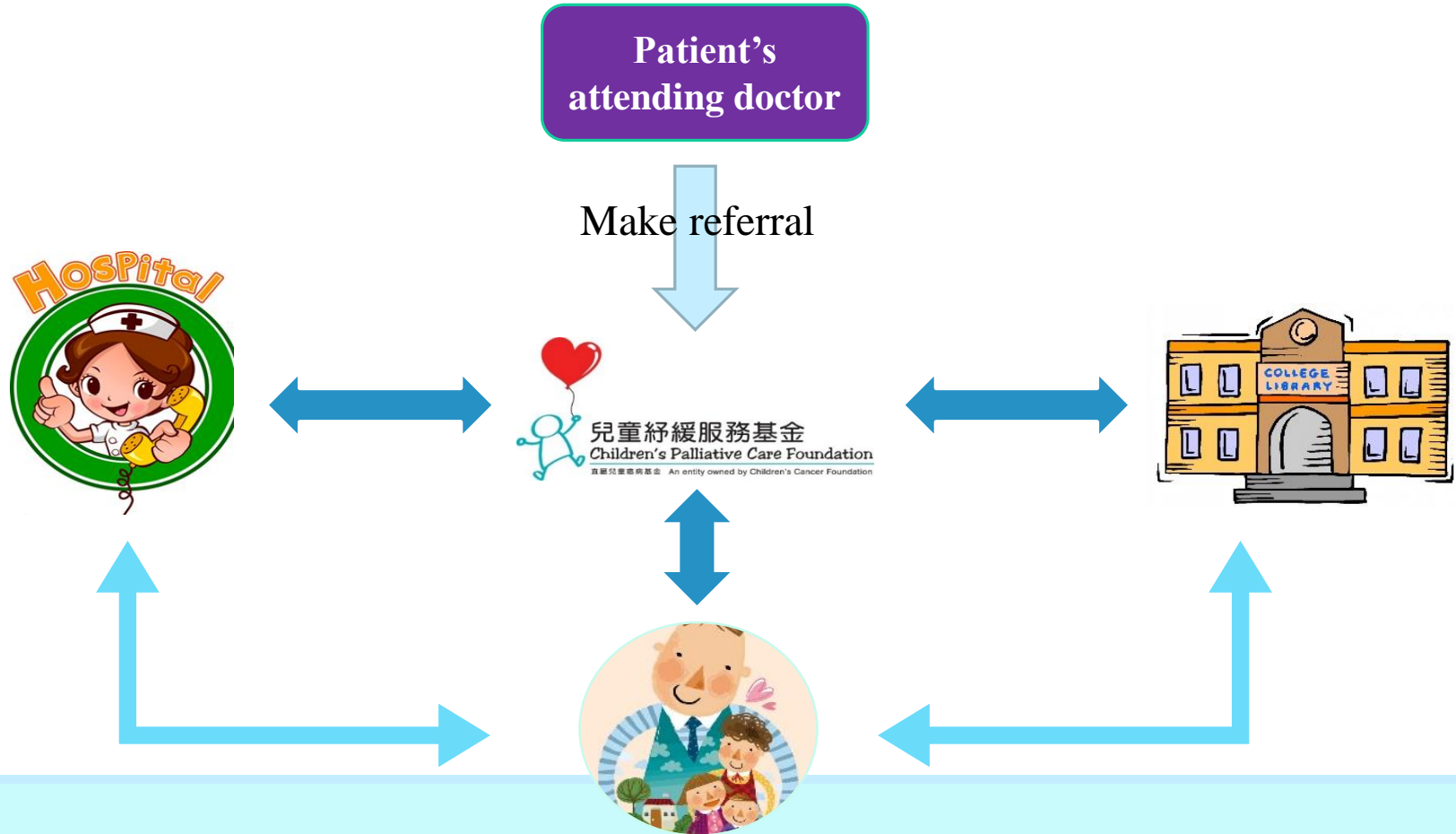
Search equipment





Community

Current service model





兒童紓緩服務基金

Children's Palliative Care Foundation

直屬兒童癌症基金 An entity owned by Children's Cancer Foundation