

Guidelines for the use of flexible support funds for children with palliative care needs

December 2005

1. Aim

The use of the flexible support funds is to meet the gaps in service or equipment availability for children with palliative care needs in the terminal phase of their illness and known to the Victorian Paediatric Palliative Care Program (VPPCP).

VPPCP was formed as an alliance between Southern Health (Monash Medical Centre), the Royal Children's Hospital and Very Special Kids and operates a consultation-liaison model of care throughout Victoria to services caring for children requiring palliative care in Victoria. VPPCP has a state-wide role and auspice in working with all children with palliative care needs and their families and carers and has established links with the key service providers involved in the provision of care.

2. Goals of funding

Many families have requirements for a range of goods and services including both in-home and out-of-home respite; and equipment including wound care, oxygen needs (not funded by Aids & Equipment Program), incontinence aids or counselling. Flexible support funds will focus on the child receiving palliative care, their family and carers, and aim to:

- Improve quality of life and symptom management;
- Optimise the capacity of individuals and families to maintain a family environment;
- Promote access to in-home or out-of-home respite;
- Provide support to families in their caring role;
- Improve options and choices about support; and
- Enable proactive intervention and minimise the occurrence of crisis.

3. Target group

The flexible support funds provide discretionary funding for children in the terminal phase of their illness, their families and carers.

4. Referrals

Referrals to access the flexible support funds can be made by any inpatient, community or consultancy palliative care service.

5. Determination of eligibility

VPPCP is to determine the eligibility of the children with palliative care needs for access to these funds. Children must be registered with a Department of Human Services funded inpatient, community or consultancy palliative care service.

6. Allocation of funds

VPPCP working in partnership with the families and carers of children with palliative care needs and their service providers can provide discretionary funding to complement the existing service system and ensure flexible and responsive support options to enable individuals to be better supported in the environment of their choice whilst receiving palliative care.

Utilising the existing Royal Children's Hospital Post Acute Care as fund holder, VPPCP would act as broker and would control access to services through the use of flexible support funds and determine which was most appropriate for the child and their family (i.e. a personal care attendant or nurse overnight in a person's home may be preferable to out of home respite).

7. Assessment

The allocation of funds will be dependant upon an assessment completed by the treating team/service providers and submitted to VPPCP. Services and/or equipment required should not be accessible through any other funding source (e.g. Post Acute Care, Early Choices, Making A Difference, Family Choice, Continuity of Care, PADP or any other funded program).

The assessment will highlight how the use of the flexible support fund will assist the families and carers of children with palliative care needs. The treating team will complete a written assessment of the needs for the child receiving palliative care and their family/carers, in partnership with the child and their family/carer. The assessment process will identify the service and support requirements and agreed goals and priorities for the child and their family/carer.

8. Care plan

As an outcome of the assessment process, a written plan is to be developed to clarify expectations and agreed priorities for the use of the flexible support funds. The plan will reflect a creative and flexible approach to responding to the assessed needs within the environment of choice for the child receiving palliative care and their family/carer. The child receiving palliative care and the family/carers involvement in the planning process and joint setting of priorities with VPPCP will ensure all options are explored and that preferences are pursued to the maximum extent possible.

9. Expenditure plan

VPPCP will be responsible for the management of discretionary payments to purchase support and services on behalf of children with palliative care needs and their families/carers as identified in the plan. An expenditure plan will:

- Consider access to existing programs and other relevant services presently operating within the service system;
- Estimate the cost of discretionary funds required to implement the plan;
- Consider the family contribution to expenses; and
- Include the cumulative costs of any funds previously contributed in the same financial year to the family.

10. Budget guidelines

To ensure adequate funding for all children with palliative care needs within Victoria, these guidelines have been developed for the distribution of the flexible support funds by VPPCP. Funds are not available for funeral expenses.

Funding will be limited according to maximum budget amounts that can be charged for provision of services, and/or equipment. These include the:

- Costs of in-home respite (a personal care attendant or nurse overnight in a person's home);
- Costs of out-of-home respite in appropriate accommodation facility (such as Very Special Kids). Bed day rate is limited to \$449 per day up to a maximum amount of \$5000 per patient.

- Equipment costs of no more than \$5,000 per child;
- Provision of home based allied therapy by a registered and/or accredited therapist;
- Counselling costs associated with the provision of specific individual, couple or family therapy with an accredited counsellor and registered agency;
- Other expenditure specifically associated with a child's medical needs.

11. Monitoring & review of plan

Monitoring and review of the plan is conducted in partnership with the child and family/carer as appropriate, and the treating team. It may also involve other key parties outlined in the plan. The process is one of mutual feedback that will vary in intensity dependant upon the plan and the needs of child receiving palliative care and their family/carer. The plan can be altered at any stage to reflect agreed changes or alterations.

12. Closure

Closure is considered when the child and family/carer no longer requires support provided through the stated objectives of the care plan. Reasons for closure may include:

- A decision by the child, their family/carer to exit the service;
- Movement of the child, their family/carer to an alternative agreement;
- Closure of the care plan by treating team in consultation with VPPCP.

13. Guidelines steering committee

A Guidelines Steering Committee will oversee this process in order to ensure equity of access to the funds and to monitor the effectiveness of the guidelines.

Membership of the Steering Committee includes one representative from Southern Health (Monash Medical Centre), the Royal Children's Hospital (RCH) Very Special Kids; one representative from VPPCP, DHS, Palliative Care Victoria and Post Acute Care (RCH) as fund holder. Representation from a parent's consumer/advocacy organisation is available.

The Guidelines Steering Committee will meet two times per year.

Referrals are to be forwarded to:

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Department of
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