French National Guidelines for PPC Pathways

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Paediatric Palliatve Care in France

Société française de Soins Palliatifs Pédiatriques

2008–2012
Created under the Palliative Care Development Programme

25
PPC Teams

1
Learned society: 2SPP (French Society of PPC)

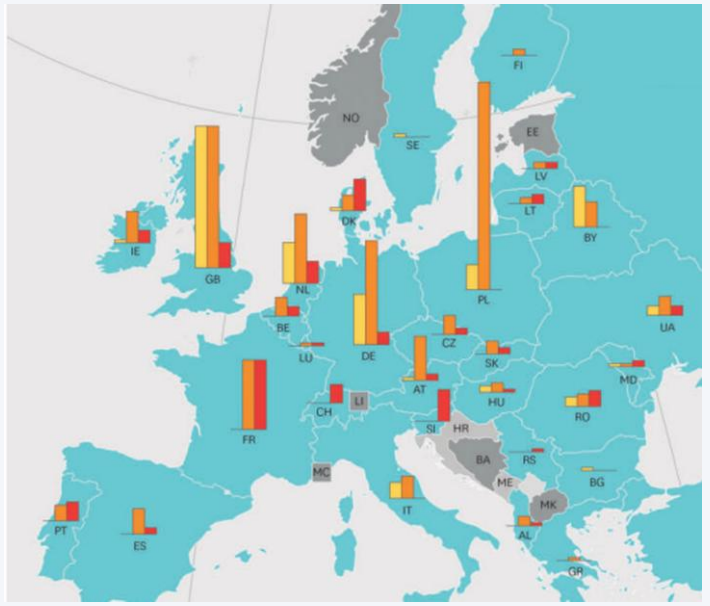
Missions

1. **Embed the palliative approach** within paediatric teams
2. **Raise awareness** among adult palliative care teams of the specific features of paediatric care
3. **Contribute to clinical research** in paediatric palliative care
4. **Ensure ongoing support** for the patient's family and loved ones
5. **Support and train** professionals and volunteers



PPC Team locations in France (2022)

- PPC Team
- PPC Team with several sites



PPC programmes in Europe

EAPC Atlas of Palliative Care in Europe 2019

- Some type of resource
- No data
- Hospice inpatient units
- Home care services
- Hospital services

Paediatric Palliative Care Pathways - Methods

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	STAGES	KEY DATES
Committee HAS Board	**1 Scoping Note & Systematic Literature Review** Drafting of the evidence report	Scoping note approved: **April 2025**
5 meetings	**2 Working Group** Expert positions and discussion of the evidence report Drafting of the initial version of the recommendations	Meetings: **September 2025 – June 2026**
Online evaluation	**3 Peer Review Group** Ratings and comments	Review phase: **March – April 2026**
1 meeting	**4 Working Group** Analysis and discussion of the peer review feedback Finalisation of the texts	Finalisation phase: **May – June 2026**
Committee HAS Board	**5 Validation and Dissemination**	Committee and Board approval: **October 2026**

Documents produced

HAS (Haute Autorité de Santé) Paediatric Palliative Care Pathways

1. **Scientific rationale**
2. **Pathway guide**
3. **Clinical vignettes**
4. **Critical points**
5. **Implementation indicators**
6. **Social support guide**
7. **Adolescent-to-adult transition guide**
8. **Summary**

GUIDE SUMMARY

Paediatric Palliative Care Pathway Guide

≈ 100,000

children in France requiring a palliative care approach

A large proportion still lack access to structured palliative care, even though their needs for symptom relief, psychosocial support and family support are considerable.

Aims of the guide

1 **Set out the pathway**

for children receiving palliative care, from the prenatal period to bereavement support.

2 **Provide shared guidance**

and involve the child and family in decisions wherever possible.

3 **Describe the organisation**

of the multiprofessional care network and coordination across health, social care, community and schools.

A care network organised in three levels

1 LEVEL 1

Palliative care approach

Provided by all healthcare professionals.

2 LEVEL 2

General palliative care

Provided by paediatric subspecialty professionals and adult palliative care teams.

3 LEVEL 3

Specialist palliative care

Provided by specialist paediatric palliative care teams (ERRSPP and EMSPP).

Central role of the PPC Teams

Implementing and coordinating palliative care plans in close collaboration with referring and local teams (community practitioners, hospital-at-home, social care facilities), drawing on hospital and community professionals as each situation requires.

A pathway in six key stages

Not a strictly linear sequence, but milestones along a continuous pathway.

1

Diagnosis

- Early identification of needs
- Disclosure of severity or incurability
- Holistic assessment of child and family
- Initial care plan

2

Living with the illness

- Regular needs assessment
- Individualised, adaptable care plan
- Psychosocial support
- Identify key professionals
- Planned transition to adult care

3

Disease progression

- Revisiting goals of care
- Advance care planning
- Holistic symptom management

4

End of life

- Comfort of the child
- Quality of the final moments
- Presence of loved ones
- Preferred place of death

5

After death

- Respect for the body and family rituals
- Help with formalities
- Screening for complicated grief risk
- Debriefing for health care professionals

6

Bereavement support

- A long, non-linear process
- Parents, siblings and loved ones
- Offered proactively, never imposed
- Tailored to needs

✓ **At every stage,** involving a specialist PPC team should be considered

Levers for improvement and outlook

Improving the quality and equity of the pathway nationwide.

Five levers identified in the guide

1. **Identify** palliative care needs early
2. **Change perceptions:** PPC is not only about end of life
3. **Strengthen coordination** through a named key professional and shared digital tools
4. **Involve the child, adolescent and family** in decisions that concern them
5. **Support the professionals** involved in care

Implementation resources: summaries, scientific rationale, practical tools, implementation indicators.

Legislative and strategic framework

- **Bill on equal access to palliative care**

  Explicitly includes PPC in the new regional care organisation.

- **National ten-year strategy (2025-2035)**

  Increase resources for PPC teams to reduce inequalities in access to care.

- **Personalised Support Plan**

  In development; will also cover minors, to anticipate and plan care and support.

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Thank you! Merci!