

Managing Uncertainty

While we were chatting among ourselves ; doctors, nurses, music therapist and counsellor, this pregnant lady walked into our clinic. She sat in front of us, without her husband at her side. Her hands were laid on her tummy, getting ready to listen to what I was going to tell her. I asked, "Do you know what is this clinic for?"

She said, "My baby has a very abnormal heart. I was told that I should come to see your team." She smiled in silence.

After I had introduced our team's role and the services we could provide, she broke into tears. She said, " I don't know what else to say. Thank you so much for everything that your team can offer. Now I feel less lonely and being more supported. Initially when I was told my baby has a problem, I am really lost. I don't know what to expect because my doctor also cannot tell me what will happen to my baby at birth. Everything is uncertain. Nothing can be predicted. "

She said, "At least, now I know there is a team here who will always be with me, to prepare for all the possible outcomes. I have come to the right place."

Three weeks later, she gave birth to a baby with severe hypoplastic left heart syndrome. Her baby passed away peacefully after 6 hours of life. She managed to hug the baby, surrounded by her family members. We kept in a memory box, the baby's foot prints and the heart beat sound, for her retrieval when she came to our bereavement clinic 6 weeks later.



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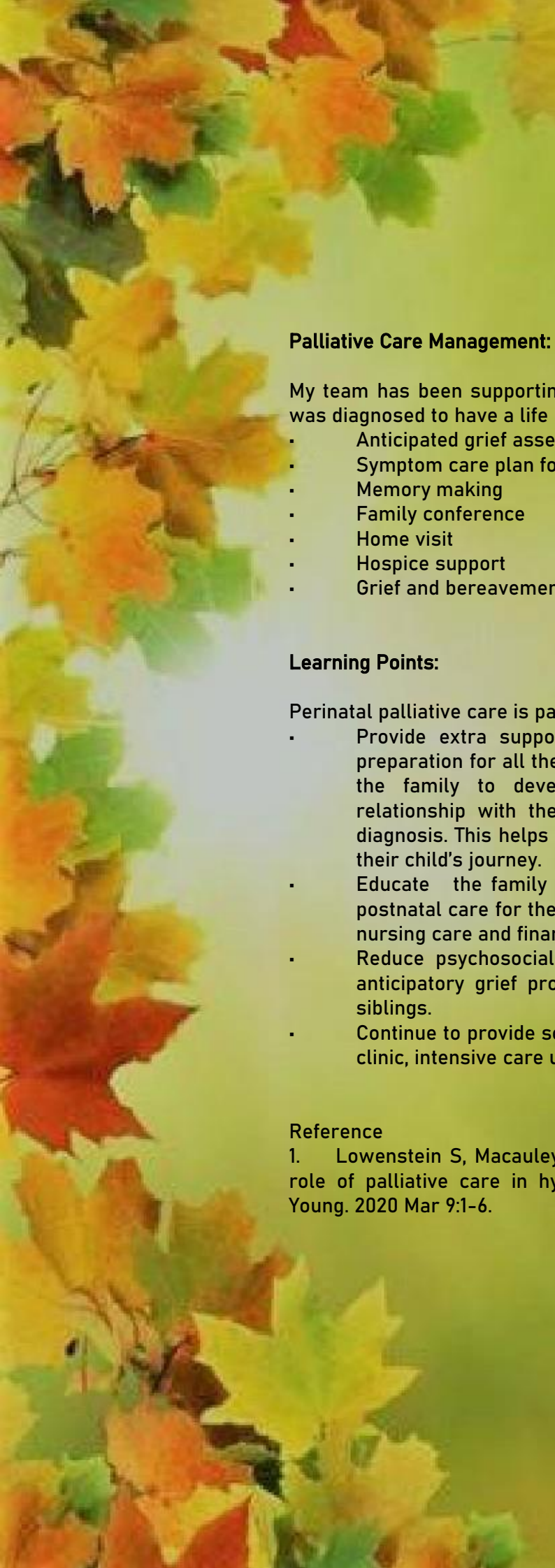
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Palliative Care Management:

My team has been supporting this lady since antenatal period after the foetus was diagnosed to have a life limiting heart disease. We provided:

- Anticipated grief assessment and management
- Symptom care plan for new-born baby
- Memory making
- Family conference
- Home visit
- Hospice support
- Grief and bereavement support

Learning Points:

Perinatal palliative care is part of paediatric palliative care service. It aims to:

- Provide extra support network for the baby, parents and family in preparation for all the possible outcomes of the baby after birth. It helps the family to develop a therapeutic and common goal-directed relationship with the palliative care team at the initial stage of the diagnosis. This helps the family to gain trust and feel supported through their child's journey.
- Educate the family about what to expect and how to prepare for the postnatal care for the baby in terms of physical symptoms management, nursing care and financial needs.
- Reduce psychosocial stress of the family through awareness of the anticipatory grief process and the psychosocial support including the siblings.
- Continue to provide seamless care to the baby and family from antenatal clinic, intensive care unit, neonatal ward and home.

Reference

1. Lowenstein S, Macauley R, Perko K, Ronai C. Provider perspective on the role of palliative care in hypoplastic left heart syndrome. *Cardiology in the Young*. 2020 Mar 9:1-6.

主題：適當地期待不確定的未知 (用愛來迎接未知)

故事：

一个日常的工作时段，我们几个人，包括医生、护士、音乐治疗师及辅导员在一起聊天。这时，有位孕妇单独走进了诊所。坐在我们面前，她抚摸着隆起的腹部，准备好听我要对她说些什么。“你知道来到这诊所的用意吗？”我问。

“我的孩子心跳很不正常，妇产科医生要我来这里见你的团队。”她带着微笑如此回答。

听到我跟她仔细说明团队扮演的角色及我们能提供的服务之后，她的眼泪瞬间滑落。我用数据跟她分析临产的几个可能性，以及医疗团队能如何协助她。

“我其实不知道该说些什么才好，谢谢，谢谢你们所做的。我现在感觉不再那么无助，也没那么孤单了。从一开始医生告诉我孩子的心脏有问题，我真的很迷茫，医生也无法告知，当孩子生出来时会发生什么状况，我真的不知道我还能期待些什么？很多事情变得那么不确定，没有什么是我可以预备的。”

“我想，我真的来对地方了。至少我知道有这样的一个医疗团队会陪着我，和我起准备面对接下来可能发生的事。”她缓缓说道。

三个星期后，她生下了宝宝，孩子有严重的左心脏发育不全综合症。也在她分娩的



寶寶的小腳丫

寶寶的小腳丫

在那短暂的几个小时，团队人员给宝宝留下小脚丫的足迹，录制了宝宝的心跳声，放入了宝宝思忆宝盒。6个星期后，这位妈妈再度回到我们临产家庭照护支援团队诊所，我们把思忆宝盒交到妈妈手中。

临产安宁照护辅助

在产检的时候，这位少妇的胎儿被诊断了心脏发育不全而可能无法存活，我们为她提供了以下的支援：

- 预期性的悲伤评估和管理
- 新生儿宝宝症状护理计划
- 创造回忆
- 家庭会谈
- 居家探访
- 安宁支援
- 悲伤以及丧亲关怀

学习所得：

临产安宁照护属于儿童安宁照护的服务之一，宗旨为：

· 给宝宝、父母以及其家人提供额外的支援服务，为他们预备分娩之后将遇到的所有可能性。在诊断之后，儿童安宁照护团队在这初期阶段能和这家庭迈向同一目标前进及达到其治疗性。同时也帮助这家庭在这过程建立信任及感到互相支持。

· 提供这个家庭相关的产后知识，如在面对产后照护时，如何准备面对孩子生理症状照护、医疗照护以及财务上的所需。

· 提供有关预期性悲伤过程的资料，减低这家庭的社会心理压力，社会心理支援对象包括家庭里的其他的孩子，因为关系本身就是最好的治疗。

· 与产检诊所、加护病房、新生儿诊所以及家庭，以无缝接轨的方式照护宝宝以及他的家人。

文献参考：

1. Lowenstein S, Macauley R, Perko K, Ronai C. Provider perspective on the role of palliative care in hypoplastic left heart syndrome. *Cardiology in the Young*. 2020 Mar 9:1-6.