This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

\*Please note: the information contained in this material is intended to provide

basic information to Batten families and caregivers. It is not intended to be, nor is it, medical advice for an individual child/ren or an individual family. Parents and caregivers should consult with their physician for specific guidance on palliative care concerns.

“Palliative Care”

Featured Expert: Kristen Drago, R.N, BSN, CHPPN

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Q: What's the definition of palliative care?

A: Palliative care is care that is focused on helping an individual with a chronic, often times life limiting but not always, condition maintain quality of life and help with managing any symptoms that are present.

Q: Can you explain what hospice care is too?

A: Often times palliative care is provided in the home through an inter-disciplinary team of nurses, doctors, social work and integrative therapies.

Q: Is palliative care only for children?

A: So hospice care is care provided to an individual with a life-limiting condition where there are no further curative treatment options and goals have transitioned to comfort care. You can be on hospice longer than the 6 month limit often times heard about.

Q: Why would some states not have pediatric palliative care programs?

A: Palliative care is for any age individual, adult or child. So palliative care in general is an emerging specialty, so pediatric palliative care is even newer. Unfortunately some states do not have funding for a state-funded pediatric palliative care waiver. Hospice and palliative care companies/organizations can still choose to have a pediatric-specific program, but this is still more often seen in larger cities/urban areas. These programs are generally provided through a non-profit, since reimbursement can be challenging.

Comment: My state (Massachusetts) is the opposite...we have palliative care for children but not adults. My sons are 23 and 27.

Q: I have not heard that before! I'm sorry to hear that. Do they have caregiver assistance/respite services where you live for adults? Also, have you spoken with a local hospice program to see if they could help with care of your sons?

A: They have helped for a few months by hospice care, but then they eventually discharge us. We have been discharged from three different agencies since October 2014 because of no nursing skills needs.

Q: Can you tell me what care needs your sons currently have? Also, if they have hospice care covered by Medicaid, you can appeal the discharge decision and ask for a review. BDSRA could provide a letter of support for the appeal if you would like one.

Comment: That might help! Thank you! Their needs vary; they can be great for months and then need constant care for months.

A: So when someone is enrolled in a hospice program, they are evaluated at set intervals for eligibility to remain on hospice. 90 days post admission, then again 90 days later and then every 60 days after that. For an individual with a neurological condition like Batten disease, they would be looking for any changes in neurological status, any infections during that certain period, weight loss, increased symptoms like seizures or respiratory management needs, skin or wound care concerns.

Q: Can you talk about how you do initial meetings with parents who request palliative care?

Q: What exactly is a state-funded pediatric palliative care waiver?

A: Kristen is going to comment, but I also found this for CA: [http://www.dhcs.ca.gov/.../PFCAgencyProviderManual.pdf](http://l.facebook.com/l.php?u=http%3A%2F%2Fwww.dhcs.ca.gov%2Fservices%2Fppc%2FDocuments%2FManual%2FPFCAgencyProviderManual.pdf&h=wAQGFNT9C). The link talks about the pediatric palliative care waiver program in CA.

Comment: Thanks! It looks like I am not in one of the counties that has it.

Comment: Oh I'm sorry to hear that. It appears that services are set up like a patchwork quilt across the U.S.

A: Yes, if a parent is interested in meeting with a palliative care provider, they can call themselves or go through their physician. A physicians order is required to admit to a program but not to simply have an informational meeting. Once the information is received, a meeting is scheduled to meet the child/adult and the family in their home and review the services the program provides, as well as getting a thorough history.

A: So each state can choose to fund from state dollars a pediatric palliative care waiver. They would then also dictate the services they would cover through that - for instance some states have a waiver that is predominantly care provided in the home that focuses on integrative therapies like massage, child life, music, etc. Other states may have it be a traditional inter-disciplinary team as mentioned above. The hospice/palliative care company then receives a set dollar amount daily to provide those services. The state waives the family’s income in order to provide these services where other state funded services are income-based.

Comment: Thanks!

A: Also, most programs are 24/7 to try and help prevent hospitalizations. So a nurse can do a visit if/when there is a change and then communicate with the physician. Without a waiver program, there are very few private insurance companies that reimburse for pediatric palliative care. Medicaid, Medicare and most private insurances do reimburse for hospice care. There are more and more large hospital systems that will have a pediatric palliative care program that will consult when someone is in the hospital and also be available to see in clinic/office. But they don't always also work with a community-based program for the home based services.

A: That probably explains why we can go to a palliative care clinic in San Francisco but get no home-based services in our town an hour away. There is a significant need for home based community programs in more rural areas. Some states have pediatric palliative care coalitions working towards that and they can sometimes help families with resources. A hospice/palliative care provider has to have licensure in a county to be allowed to provide care there.

Comment: Kristen mentioned the Pediatric Palliative Care Coalition, an organization that advocates on behalf of pediatric care services. They (hopefully) can recommend a legislative champion in your state that you can work with to lobby for better services. [http://www.ppcc-pa.org/](http://l.facebook.com/l.php?u=http%3A%2F%2Fwww.ppcc-pa.org%2F&h=HAQH_AW6c)

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[PPCC | Pediatric Palliative Care Coalition](http://l.facebook.com/l.php?u=http%3A%2F%2Fwww.ppcc-pa.org%2F&h=RAQF1NV7x&enc=AZPUXiCOqvtXa3Kw4QasQ-GRjEUI2zzLE2YpRE_HKXVibFbbVDpERGIOPCpMZerPXfvqP4ZHTn9797Ae9yyljlNY4B3unxfbKwmkMYNwW_12bB-_UqJPBoGEcjx7EwyDj8j-jLHBQfe0q7-58Myz9rw1zgkHP72hJ7Q0mtkgbHEQrw&s=1)

| Pediatric Palliative Care Coalition

ppcc-pa.org

Thanks to BDSRA Board Member [Kristen Drago](https://www.facebook.com/kristen.d.drago?hc_location=ufi), RN, BSN, CHPPN, for sharing her expertise about pediatric palliative care tonight! We greatly appreciate it!

You can check if your state has a pediatric palliative care coalition to help fight for these types of services. Also, [nhpco.org](http://l.facebook.com/l.php?u=http%3A%2F%2Fnhpco.org%2F&h=fAQFfS0lJ) is a website where you can find out about your specific state as well as the federal law on concurrent care for children

[](http://l.facebook.com/l.php?u=http%3A%2F%2Fnhpco.org%2F&h=ZAQHVshR8&enc=AZPoLGMe9SUQ7i5Xbvg-yUJhl0npNBFPIaYVvi36o9mUPgZYkfAseAZp_KsW9gXml-jbYNNR3xhkxHao2UGGRPsY4iV2bTmdw5A1qJk72oz0fsy_8xysiDtdywo-uZn0Cs6MWRrHth9YWwNVBUaTP2l-cp1xjwhc-WxVpO11SorC_w&s=1" \t "_blank)

[National Hospice and Palliative Care Organization](http://l.facebook.com/l.php?u=http%3A%2F%2Fnhpco.org%2F&h=6AQF0QSeh&enc=AZNuRlF1XTHkiPpH-QqBRpYdbQSDyeiXdX21bk3wG_yNldJh9Qui4BLzssDHg8kK4NmTr25JWseZ6bq5fSN3cz-wESQ0__0wV_oQmimGPKvdrCzicJYV1gNUtQ_IYrireQozGAOQurkq4iDHR8d7WQOoPbrj4xN93QD-dhm5f67quA&s=1)

Showing the world that hospice is about more than care for the dying. Hospice and palliative care can make more meaningful moments possible.

nhpco.org

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