

## Featured Innovation

### **Integrating Palliative and Curative Approaches in the Care of Children with Life-Threatening Illnesses: An Interview with Ann Goldman, MB, FRCP**

*Dr. Ann Goldman, a palliative care specialist and pediatric oncologist at Great Ormond Street Hospital in London, England, describes the pediatric palliative care program she initiated there 14 years ago. Fully integrated within the pediatric oncology-hematology department, the pediatric palliative care team at Great Ormond Street Hospital works with a child and family, from the time of diagnosis throughout the disease trajectory, to manage symptoms and provide a range of supportive services in coordination with local care providers after the child is discharged from the hospital. Dr. Goldman's program has inspired other pediatric palliative care initiatives in the United Kingdom, Canada, Australia, Hong Kong, and other parts of the world. In the following interview, Dr. Goldman explains how her program developed and what new efforts are underway in England to improve pediatric palliative care. [Citation: Goldman A. Integrating Palliative and Curative Approaches in the Care of Children with Life-Threatening Illnesses: An interview with Ann Goldman, by KS Heller, *Innovations in End-of-Life Care*, 2000;2(2), www.edc.org/lastacts]*

#### ***What palliative care services are available in Great Britain for children with life-threatening conditions and their families?***

Palliative care in pediatrics in Britain started in the mid-1980s, in two different areas. One was to set up an area of care for children dying from malignant diseases in oncology units, and the other was to establish children's hospices. In this country, when we say "hospice," we tend to mean a facility, a building, as opposed to how the word is used in the United States, where it tends to refer to a service in a much wider sense. So, in this country, the oncology units were all becoming aware that they needed to focus on children who were not going to get better, and to develop the services that would enable children and their families to have a choice and to have support and symptom management in that final stage of life. The oncology centers set up clinical nurse specialists whose role was to be involved with the children from diagnosis, but particularly to facilitate home care and palliative care if that were needed. In the whole of the United Kingdom, there are about 22 oncology centers, and, since the mid-1980s, each of those has developed some sort of specialist service for palliative care, based from the oncology center and reaching into the community.

However, we have tried to be conscious that it's not just children with cancer who need palliative care, but also children with a wide range of diagnoses, such as metabolic and degenerative diseases. Those families were feeling very much in need of more respite care and support than they were getting. The children's hospice movement has focused more on the patients in those groups.

These are freestanding, charitable hospices. Helen House was the first one, in Oxford, and there are now 20 of them around the country. They're small, home-like units—not like a big medical facility. There are maybe eight bedded units that link with the families, offer respite for both the children and families, support the parents and siblings, and also do bereavement work.

***Is there any pediatric palliative care provided at home?***

The oncology centers are all doing home care and many local hospitals do, too. Because our health service is so different, in a way, from yours, we have always had greater linkage with and support from providers in the community, because every family has a family doctor. We also have always had some form of community nursing services; over the last ten years, pediatric community nursing which is quite often linked to a local pediatric unit, has also developed. Our patients come from quite a wide geographic area. So, as a team based in an oncology unit, we work alongside each patient's family physician and community nursing service.

***Does that make for good continuity between what goes on in the hospital and the care provided when patients go home?***

That's the idea, but of course it works better in some places than in others, and the services are more complete in some areas and more sparse in others.

***What are "Diana nurses," and how do they fit into this system of care?***

Pediatric community nurses have been around a long time. In memory of Princess Diana, the government put aside some money to try some new pilot projects with more coordinated local services. People could apply for these funds to try to develop a palliative care team in a local area to cover nursing, but also perhaps to be able to offer respite care and bereavement support, such as more physiotherapy, or whatever is needed in a local area. So, the Diana teams, which provide palliative care services specifically for children, are funded by the government and are a way of filling out what services are already there in a more comprehensive way.

***Are there inpatient pediatric palliative care services within the oncology centers as well?***

The oncology centers will always readmit a child for palliative care if that is needed, or the children could be admitted to their local pediatric ward, but neither of these are specifically designated or planned areas for palliative care.

***How many children die in Britain each year who might benefit from palliative care services?***

A good source of this information is a recent report from a joint working party of the Royal College of Pediatrics, which is the British equivalent of the American Academy of Pediatrics, and the Association for the Care of Children with Life-Threatening Diseases and their Families (known as ACT), which is a charity.<sup>1</sup> The working party was interested in developing and integrating services for children who needed palliative care. Until very recently, nobody had thought about these children as one group because they represent quite a wide spectrum of diagnoses, many of which are rare illnesses, and they are geographically scattered all about the country. But we collected what data was available. We reckoned that for every 100,000 children, there were likely to be 100 who had some sort of life-limiting condition at any one time. About half of those (50 per 100,000) would need active palliative care at any one time. One could expect that each year about 10 per 100,000 children would die from a progressive disorder or a life-threatening condition of some sort. That excludes acute trauma, which is the most common cause of death for children over one year old; and acute infectious diseases like meningitis; and neonatal deaths. Since we published that data in our report, colleagues in Canada and other places have confirmed that their figures are very similar.

The working party then defined some categories of children whom you would expect to need palliative care. We found that there were four groups: one group includes children who have conditions for which curative treatment is possible, but may fail; you would think of cancer in that

group. The second group includes children with diseases from which premature death is very likely, but for whom long periods of quite intensive treatment can prolong good quality life. This group would include children with cystic fibrosis or muscular dystrophy, or even HIV and AIDS, in which quite intensive treatments, including intensive care units and even ventilation, might be appropriate at some points in the illness, but ultimately these are illnesses that we can't cure. The third group includes progressive conditions, in which treatment is really palliative from the time of diagnosis, and some of these conditions extend over many, many years. So, this group includes some of the genetic disorders, some of the mucopolysaccharide disorders, some neurodegenerative diseases, such as Batten's disease or Tay-Sachs disease, and others. The fourth group includes conditions that are not progressive themselves, but render the children so vulnerable and susceptible to serious complications that their life expectations are actually very shortened. So, children who have severe cerebral palsy or massive brain damage or other such conditions might be included in this group. It has been quite helpful for people here to define these four groups of children whom one needs to be thinking about in planning and developing palliative care services.

***What brought you into the palliative care arena, and what is the underlying philosophy and model of care that you've been undertaking in your own setting?***

I was a pediatric oncologist. Around 1985–86, I became aware that, as pediatric oncologists, we spent a lot of time and energy thinking about all the different tumors and what was going to be our next protocol for lymphoma or rhabdomyosarcoma. When children were not going to be cured, we put a lot of time and effort into caring for them, but we didn't think about it in a structured way. So, I thought that we needed a few people to focus on supportive and palliative care. I was also aware that there were families who wanted to look after their children at home, but who didn't feel they had adequate support in the community and expertise available to them to be able to do that. To get support for this within the department, I first spoke to the senior people about whether they would be interested in having a symptom care team. They said, "We haven't got any money, but if you can find the money, we'll be glad to have you." So, with a couple of nursing colleagues whom I knew were thinking in similar ways, we spent about a year finding a charity that was able to fund us, and then came back and set up the team.

***Once you got funding to set up a palliative care team, did you face any barriers in implementing this concept? How was this service received by your oncology colleagues?***

I think it was extremely welcome, actually. People were really very open to the idea and keen to look after the children in an optimum way. I think I have had less difficulty than some of my colleagues, particularly in North America. I think it helped that I was coming from within the unit and had an oncology background myself. It also helped that I was not coming in as an attending physician, but rather in a position equivalent to a senior resident, so people felt confident that they were still in control of their own patients. After a couple of years, I got promoted to the equivalent of an attending—what we call a consultant here—and by then people felt confident in working with me as a palliative care physician.

***Do you believe that it's really possible to integrate palliative with cure-oriented approaches?***

Yes, I do. As a team within the oncology unit, we do integrate these approaches, insofar as we meet our patients at the time of diagnosis. We're not only the symptom care team, we're also the home care team and we share the patients among members of the team according to geographical area. We visit each patient quite soon after he or she is first discharged from the hospital. We also do school visits, to help integrate children back into school. We visit the family doctor and whoever else is important and needed in that child's life, such as the play school or the grandma.

***How many people are on your team?***

There are three nurses and me, and the secretary who looks after us all. But we work with the rest of the oncology department, so we work with the social workers who are part of the oncology department, as well as the rest of the nursing and medical team. We're very much a part of things all the way through, and we often have quite a lot of input at the beginning with a family, to help them get over the hurdle of diagnosis and get integrated into treatment and back into home life as well. Then we may take a much lower profile while the child's coming up regularly for therapy. If the child relapses, however, the child and family already know us. So, we're often part of discussions with the family and the physician—and perhaps other nurses to whom they feel very close, about what to do next.

***How are you introduced to families at the time of diagnosis? How is your role described?***

We are called the "symptom care team." At the beginning, sometimes, we will say we're the "home care team." Most people don't take very long to realize exactly what we do, and occasionally we'll have families who will say, "I don't think we want your help, please. We'll call you when we want you," because of the implication to them that our involvement means that their child isn't going to get better.

***Do you consult with your colleagues regularly on pain and symptom management throughout the disease trajectory? Or do they do that themselves?***

On the whole they do it themselves, but they might consult specifically with the team if there are particular problems.

***At diagnosis and during the period of intensive, cure-oriented treatment, does the symptom care team focus primarily on the emotional impact of the illness and the psychosocial aspects of care?***

Yes, and we work with the ward team and social workers in this. We might also deal with symptom management if there are particular issues. We serve as a liaison, coordinating with the local hospitals and the local medical teams. Then, toward the end, if the child is relapsed, he or she may go back onto a little more treatment to prolong good quality life, if everybody thinks that seems a sensible thing to do. We'll then work much more closely alongside the family in thinking about what might be needed down the road. I think that helping the child and family prepare for what may lie ahead makes a huge difference. In oncology it's terribly important, but it's even more important with some of the other diseases and conditions in which the transition to a downward course may be much more blurred. However difficult it is in oncology, cancer is a progressive disease that makes its mark felt in the end, whatever you do; whereas, with some of the other illnesses, the transition is much vaguer and happens over a long period, and it's harder for everybody to see it happening at the same time.

***How do you sustain hope while at the same time help people anticipate that there may be things they'll need down the road if the child does not do well?***

I think people are a lot more aware than we sometimes give them credit for. Just as children are a lot more aware than we sometimes acknowledge, so are parents. If they're coming regularly to a unit that is looking after children who have a life-threatening disease, they meet other children for whom things are not going so well. People may choose to cope by not addressing it at the forefront of their mind, because you can't always live day to day if it's in the top of your mind, but most people know

it's there. When you tell some parents, "The disease has come back, and I'm not sure that we're going to be able to cure it anymore," they will say, "I've always known this was going to happen." On the other hand, other parents will say, "I can't stop even though you tell me that, and in a way I believe you. But I wouldn't feel I was being a parent if I didn't keep fighting." Everybody's different, and I suppose one of the things we have to do is try to be very flexible.

***In a situation in which the child is going downhill and the parents have not yet fully accepted this, how do you coordinate your efforts and goals of care with those that continue to aim for a cure?***

By taking the philosophy of palliative care into the situation, even though treatment may still be going on, which the parents hope and pray may cause a miracle, but which some of the rest of us don't think will occur. All parents are terribly keen to do what they can to avoid their child suffering. If their child is having further treatments but nevertheless has a progressive disease and is uncomfortable, the child will need pain management. If the child has a brain tumor, for example, and is becoming less able to do things physically, to speak, see, or hear. If different parts of the child's life are being affected, the parents will want help to manage those aspects of care. I suppose what we're trying to do is to help parents see that sometimes, being the very, very best parent—which is what every parent wants to be—does not mean fighting to cure, but fighting to do the best you can for your child's quality of life at this point. It is as though we give people permission to still be a good parent by making a very difficult choice.

***In your setting, have you encountered any reluctance among your colleagues about discontinuing cure-oriented treatment and moving entirely to palliative care, perhaps because of an unwillingness to acknowledge that treatment has failed and that the child is dying?***

There is always, I think, a sense of deep sadness when you cannot cure a child. But there is also a recognition that when that happens, our responsibility is to do the very best we can for the child, which may not always be to cure. Some physicians find it harder to let go than other physicians; some families find it harder to let go than other families. There's a great spectrum. I would say on the whole, however, one is able to find a middle ground where everybody comes to much the same conclusion at much the same time.

I think that compared to the States, the choice not to continue further curative treatment is made a little bit more easily here. It varies, obviously, with different diseases and different children and different situations, but in general I think people in the States would agree that we don't use quite as much experimental treatment as you do.

***If there is disagreement among the care providers about what is the appropriate thing to do for a child—for example, whether to discontinue cure-oriented treatment and provide only palliative care—how is that handled?***

I think people move at a different pace, sometimes. Sometimes I'm asked to help around the hospital in cases with non-oncology patients because there can be difficulty over this time of transition. Often this may be because the nurses, who are working very closely with the child and family, are getting to the point where they can see that a cure is not going to be likely, before the doctors do. But the ultimate responsibility for the patient lies with the doctors, so it's not unreasonable that they should make quite sure that in every way they're convinced that a cure isn't attainable. And unlike the nurses, they're not with the child day to day to see the extent of the child's suffering. So, I feel some of my role is to try to help with that sort of transition. It isn't always easy.

***How does the symptom care team generally coordinate its work and communicate regularly with other members of the child's care team? Are there regularly scheduled team meetings to review and discuss the goals of care on an ongoing basis?***

Members of our team attend the major ward rounds of the week and the major psychosocial meeting on the ward. We also have our own symptom care team meeting for the patients who are having primary palliative care. Most of the children we see want to be at home, and most of our families want them to be at home once they realize that a cure is not likely. So, at that point the children and their families begin to have much less to do with the physicians who've been involved with curative treatment and much more to do with our team and their local carers.

***Do you advise and assist the local care providers, or does your team provide home care directly?***

I think we try quite hard to work with people in their local communities, partly because the children live at quite wide geographic distances. We can't possibly offer 24-hour on-call care for every child in every emergency situation; it would take us two, two-and-a-half hours to get to some of them. So, we work very hard to establish a local support network, and we offer a 24-hour on-call advisory service, for both the families and the local carers to phone us.

***What do you think might stand in the way of adapting your model of care in other settings? How might it need to be modified?***

I don't think you can translate what I've done elsewhere. You have to take the principles and work those, within the constraints of your own healthcare system. I know, for example, one of the barriers in the United States has to do with insurance and financing palliative care services, which is easier in Great Britain because we have a National Health Service.

***Have you done any kind of formal audit or evaluation of the benefits of your service? If so, how do you measure your success?***

One of the things we know is that from the moment we set the team up and were able to offer people much more support at home, the number of families who chose for their child die at home increased from about 30 percent to 70 or 80 percent. This occurred even though our goal was *not* to encourage people to care for their dying child at home, but rather to improve palliative care wherever the family wanted that to be. But "wherever" turned out to be at home, if you offered the right service. So, I suppose that is a very clear measure of providing something that didn't exist before. Outcome measures are actually quite difficult. Even in adult palliative care, there's been relatively little in the way of formal tools to evaluate quality of life because the sorts of tools you would use depend on people getting better, and all these people are getting worse. One has to develop a whole different way of measuring quality of life, and that's only just beginning to be available for adults and isn't really available yet for children.<sup>2</sup> Professor Irene Higginson, from King's College and St. Christopher's Hospice in London, and I are hoping to look at what might be appropriate ways to evaluate quality of life for pediatric palliative care. But it's difficult to do, and what you need to look at for oncology patients is different from what you would look at for a neurodegenerative disease that goes on for more than 12 years. We're still trying to figure out what would be appropriate measures.

***Has the model of pediatric palliative care that you developed at Great Ormond Street been adopted elsewhere in Britain, or elsewhere in the world?***

In the UK, all the oncology centers have some sort of pediatric palliative care system and team; many of these were developing around the same time as our team. They are not identical to one another but many have a lot in common. What's a bit different about our particular model is that we've had a physician for whom this is the main interest involved right from the start, whereas the others have worked with the oncologists.

In Canada, Stephen Liben in Montreal and Gerri Frager in Halifax, Nova Scotia, who both spent some time with us here at Great Ormond Street, took our ideas back home and have developed their own teams. Steve Liben comes from an intensive care background, so his approach is slightly different, and Gerri Frager comes with a lot of skills in pain and symptom management, which has influenced her approach. Each person, I think, develops his or her own pediatric palliative care program according to his or her own skills and roles in that particular healthcare system. People in Sydney and Brisbane, Australia have also looked at our model and gone back and developed what seems to work for them. Similarly, people from Hong Kong have visited our hospital, and I've been over there to have a look with them at how to begin to develop pediatric palliative care. So, I think the interest in pediatric palliative care and the development of these kinds of services is spreading quite a lot more now.

***What more would you like to see happen to improve pediatric palliative care services now?***

I'd like to see what is a reasonably well-developed model in oncology further develop so that children with other life-threatening illnesses are also being cared for in a more equitable way. Not in the same way, because the diseases and the needs are different, but that their needs are being thought about and services are being provided for them. I think that's quite a big and important issue. And from my point of view, much more physician training needs to be done in this area. In Great Britain, there's me and only one other full-time palliative care pediatrician, and one other who does this part-time. The other two are in Cardiff, Wales, and Southampton, England. In addition, there are a lot of pediatricians who provide quite a lot of palliative care, but without calling it that. We need to make palliative care a real special interest within pediatrics and develop the training programs and structure within our system to accomplish that.

We've made quite a bit of progress, in that the first step on the way to being considered a pediatric specialty is for the Royal College of Pediatrics, which governs specialties, to invite you to form a college special interest group. We have done that. And we have been given the go-ahead to try to make what was recommended in the report of the joint working group of the College of Pediatrics and ACT really happen. So I think we have a lot of support for the area of palliative care, but making it happen in reality when you have to fit in with all the other things that are needed within a healthcare service always takes a lot longer than you hope because you're queuing up with everybody else to get things done.

***Is pediatric palliative care on medical school agendas in Great Britain?***

Adult palliative care has made it to medical school agendas, but this differs depending on the medical school. I think we'll be able to work toward getting it into pediatrics by perhaps persuading some of the people who are involved in writing the professional exams to include questions on pediatric palliative medicine. We've already broached that, and they're quite happy to do it.

***Have you and your colleagues been working on any standards or quality indicators for pediatric palliative care that could be used as benchmarks for this growing field?***

We're thinking about developing standards in association with training. One of the things we'll be

doing is putting together a syllabus for physicians of what they will be expected to know. So, perhaps the syllabus might be a start in that direction.

The nearest we are to setting standards and benchmarks for the kind of care we hope people will achieve is in the recommendations for the development of services that the joint working party of the College of Pediatrics and ACT put together, in which we articulated what we thought every healthcare district ought to have in place. Those recommendations focus on the provision of services, rather than on such standards as, "Every pediatrician will know what dose of morphine to give a child." It's not a formal benchmark document, but those recommendations state what we'd like to see reproduced over the whole country. In addition, through ACT, we are working with a number of local areas to try to develop coordinated pediatric palliative care services.

***What are the major things you've learned from the process of creating and sustaining a palliative care program for children with cancer?***

Palliative care is not dependent on *one* person's skills; it's very much a team undertaking, working alongside other people and with other people. In addition, I think I've learned a huge amount about how amazing people are from watching families deal with what are such awful and difficult circumstances.

**References**

1. Association for Children with Life-Threatening or Terminal Conditions and Their Families and the Royal College of Paediatrics and Child Health. *A Guide to the Development of Children's Palliative Care Services*, 1997. To access this publication, visit <http://www.act.org.uk/actwebnew/publications.htm>
2. To read more about this issue, see *Innovations in End-of-Life Care*, Vol. 2, No. 1, 2000, "Measuring Quality in Palliative Care," with interviews with Irene Higginson, PhD, and Franco Toscani, MD. You may access this issue from the [Archives](#).