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# **Balfour Mount Oral History.**

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#### **Biography**

Dr. Balfour Mount is a medical graduate of Queen's University, Kingston, Canada. He trained as a Urologist at McGill University and as a Surgical Oncologist at Memorial Sloan Kettering Cancer Center, New York. He was the Founding Director of the Royal Victoria Hospital Palliative Care Service in 1975, Palliative Care McGill in 1990, and the McGill Programs in Whole Person Care in 1999. He is an Emeritus Professor of Medicine at McGill University where he held the Eric M. Flanders Chair in Palliative Medicine.

Dr. Mount's research interests include quality of life. He is an author of 148 publications and has participated in the production of 25 teaching films and audio tapes. He has been a lecturer and Visiting Professor in North America, Great Britain, Norway, Holland, France, Austria, Italy, USSR, Japan, Australia, New Zealand, China and Taiwan. He was the founder and Chairperson of McGill's biennial International Congresses on Care of the Terminally Ill. He is an Officer of the Order of Canada, an Officer of the Order of Quebec and recipient of the American Academy of Hospice and Palliative Medicine 'Lifetime Achievement Award'. He has been honored through the creation of three named awards: 'The Balfour M Mount Award' of the American Journal of Hospice Care, 'The Royal College of Physicians & Surgeons of Canada Balfour M Mount Visiting Professorship in Palliative Medicine,' and 'The Balfour Mount Leadership Award in Hospice Palliative Care' of the Canadian Hospice Palliative Care Association.

#### **Interview Abstract**

Dr. Balfour Mount begins the interview by describing a pivotal moment when he heard Dr. Elisabeth Kübler-Ross lecture at McGill University's Royal Victoria Hospital. Dr. Mount had not previously heard of Kübler-Ross's work and was impressed to learn about the unmet needs of the dying. When Dr. Mount conducted a similar study at the RVH, he found the same deficiencies in care and carried out a two year pilot project aimed at addressing these needs through the creation of an in-patient ward, a consultation service, a home care program, an outpatient clinic, and a bereavement follow-up service.

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# **Glossary of Acronyms**

Abbreviation	Definition
CBC	Canadian Broadcasting Corporation
GI	Gastrointestinal
ICU	Intensive care unit
IV	Intravenous therapy
RVH	Royal Victoria Hospital
PCS	Palliative Care Service

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# **Interview Roadmap**

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\*\*Edited for grammar and content by Dr. Mount. Additions and redactions indicated by brackets and ellipses, respectively.\*\*

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[00:00:00]

**Bryan Sisk:** Today is August 1<sup>st</sup>, 2019. I am Bryan Sisk and I'm in St. Louis,

Missouri interviewing Dr. Balfour Mount over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Mount is in Montreal, Quebec, Canada. Thank you, Dr. Mount, for joining me

today. To get us started—

Balfour Mount:

It's a pleasure Bryan.

[00:00:20] **Bryan Sisk:** 

You started your career as a urologist and a surgical oncologist. Could you tell me a little bit of how you became interested in what

eventually became palliative care?

**Balfour Mount:** 

I was, as you say, a surgical oncologist. My training was at McGill and at Memorial Sloan Kettering Cancer Center in New York. My point is, that my training, interests and goals were related to surgical oncology, with no eye to anything else. One day in 1972, I learned that there was going to be a lecture at the medical school that afternoon given by Elisabeth Kübler-Ross. I had never heard of her. At the lecture, Elisabeth discussed her book *On Death and Dying...* 

At the end of the lecture, I was impressed by the evidence of inadequate care for the terminally ill in our healthcare system. At the time, the practice was to refer dying patients to nursing homes where the quality of care was variable and largely undocumented. I was fascinated, because 70% of us... die in institutions. So, how we die is of some significance and I thought after hearing Elisabeth that it should be a simple thing to do a study examining these issues at the Royal Victoria Hospital... I was confident that our hospital provided excellent care.

As a result, we did a study... What our study demonstrated was the significant unmet needs of the terminally ill: poor pain and symptom control and inadequate attention to the complex needs of the therapeutic triad (By that, I'm meaning the patient, family members, and caregivers)... The findings were disturbing and my recommendation was that we develop a program to address the unmet needs we had uncovered.

In the process of our background work and writing up our findings, I got to know Elisabeth very well and she became a close friend. I also learned about St. Christopher's Hospice in London, where, in 1967, Cicely Saunders, later to be Dame Cecily Saunders, a British physician who had previously also been both a nurse and a social worker, established St. Christopher's Hospice for the terminally ill.

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I visited St. Christopher's and was impressed by the excellence of their approach. Dr. Saunders invited me back the following summer (1974) to work as a member of their attending staff in her absence...

Our recommendation on documenting the deficiencies we had found, was that we develop a hospital based program that included an inpatient ward, a consultation service, a home care program, an outpatient clinic, and a bereavement follow up program, as well as research and teaching activities...

Here in Quebec, in a francophone milieu, the word "hospice" has a negative connotation... With that in mind, I thought of the word "to palliate," meaning "to improve the quality of.". Thus, our new program became the Royal Vic Palliative Care Service (PCS)... In due course, my commitments to palliative care became so time consuming that I finally left my surgical practice at McGill and concentrated solely on the needs of the dying.

In the mid 1980's, I was invited to evaluate end of life care at the Montreal Children's Hospital. Our findings evoked a renewed interest in the needs of the therapeutic triad in the pediatric setting...

[00:19:09] **Bryan Sisk:** 

When you published these reports showing deficiencies in end of life care, how was that viewed by the administrators and the academic leadership at the institution? Was that something that they welcomed or something that they were concerned about the image that you were going to portray with the data?

**Balfour Mount:** 

I don't remember any concern about image, and I guess that might be surprising. These are really first rate academic institutions and you just have to get the cards on the table and get well documented evidence. It's not a matter of being critical, it's a matter of documenting the problem and then asking how we can address it. Paradoxically, Bryan, it was quite the opposite. It's fascinating, isn't it? ... To divert academic beds and by implication, funding, from medicine, surgery, and the other programs at our teaching hospital that were already underfunded, in the interest of caring for the dying and to take those steps in the interest of something with a new name called "palliative care" - What in the world is that?! - Our data had to be clear. The discussions were pointed as to why we should be doing it in these teaching hospitals. It was an interesting, challenging and exciting time...

[00:22:15]

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Bryan Sisk:

I was asking if there was any push back to showing the dirt beneath the rug.

**Balfour Mount:** 

No, it attracted an incredible amount of very positive support through newspaper, radio and television coverage in both English and French, as well as public support financially for the program. The public saw it as a positive response to an important healthcare problem...

[00:24:02] **Bryan Sisk:** 

So when you were making this transition from surgical oncologist, which I assume was competitive and difficult to get that position, and then you had to tell your colleagues, "I'm transitioning to do full time palliative care." Did you feel supported? What was that like?

**Balfour Mount:** 

Bryan, it was a series of events that I would love to take credit for, but the fact is, it was a chain of events that was unpredictable. It was almost unnerving how doors opened and opportunities presented themselves that one could not have anticipated...

Because I had a busy research program, a teaching program and a surgical practice, I needed a full time physician to be on the palliative care unit... I was flying back from St. Christopher's, and somewhere over the Atlantic I thought, "Well who in God's green earth do I know who could do this?" And no sooner had I recognized the question *who* could do this but the answer Ina Cummings came to mind. Well that was unanticipated! I didn't know Ina. We had only been briefly introduced once at a meeting we both were both attending...

I looked up her number and phoned her... I told her about St. Christopher's and about the findings of our Royal Vic study, adding, "I wondered if you might be interested in hearing more and perhaps taking part in this project?" It seemed a bizarre question. Her response was stunning, "It's very strange you should call right now. I've had the strongest feeling recently that I should be changing what I'm doing." ... That sort of thing kept happening

In response to your question, yes... There were some serious objections, but the doors unexpectedly opened... [00:33:11]

Bryan Sisk:

You mentioned that in the early '80s the Montreal Children's Hospital invited you to look at their end of life practices. Were there any pediatric palliative care programs at that time, or was that something that came up later on after it was primarily established in adults?

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**Balfour Mount:** 

In the early 1980s when I did the palliative care assessment study at the Monreal Children's with my colleague Dr. Linda McHarg... I was not aware of other pediatric programs. There were two adult home care programs, - one in California and one in New Haven, Connecticut based on Cicely's model but no pediatric programs...

[00:35:35] **Bryan Sisk:** 

I've heard from a number of people who were foundational in picking up the mantle and carrying it into pediatrics, who had sought guidance from Cicely Saunders. And it sounds like initially she had a lot of resistance or lack of comfort with thinking about expanding hospice to pediatric-based care as well. Did you have any of those types of interactions with her in your discussions?

**Balfour Mount:** 

Any skepticism Cicely had was related not to her understanding or lack of understanding of the need, but to her feeling that there would be opposition in a traditional academic teaching hospital setting. Funding everywhere was so tight and the pressure on bed utilization was extreme. It was generally believed that this was not what these beds and programs were for in the tertiary care setting. When Linda and I did the palliative care assessment study at the Children's, we were impressed by the potential at hand if Cicely's findings were to be applied in the pediatric setting...

I was really moved by the involvement of the families and particularly the mothers of these children and very deeply touched by it.

I remember a newborn with multiple congenital anomalies whose condition was beyond any surgical correction. This poor little tyke was dying and... I became aware of how upset the infant was. The baby was in a bassinet with oxygen but was restless and clearly distressed. I placed a tape recorder in the bassinet and played some gentle, relaxing music. Then, I added the tiniest drop of dilute opioid liquid under the baby's tongue. The suffering and the distress dissolved... I was profoundly impressed that the simple strategies that we were using and finding relevant in the adult situation were totally relevant and transformative in the pediatric context.

[00:42:26] **Bryan Sisk:** 

That's very interesting. Do you think that the other clinicians were not able to recognize the suffering or do you think they recognized it but felt they didn't know what to do? ...

**Balfour Mount:** 

Well, the interventions were relatively simple, , straight forward and transforming.

[00:43:13]

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Bryan Sisk:

Did it seem like there was an awareness of the degree of suffering present in these kids or did it seem like it was under appreciated?

**Balfour Mount:** 

Oh it was appreciated. In fact, the attending Pediatric Fellow was having his second attempt to establish intravenous access via a scalp vein... Following my intervention, the infant promptly settled.

. . .

I left the Children's with profound respect for the nurses, the pediatricians, the little tykes who were dying, and the family members.

. . .

[00:54:58] **Bryan Sisk:** 

From being a major part of this development in adults and observing on the outside the development in pediatrics, do you get the impression that palliative and hospice care should be considered an overarching specialty in which the care for adults and care for children fall in it? Or do you get the sense that pediatric palliative and hospice care is unique enough that it merits its own specialty, own field?

**Balfour Mount:** 

Well, I don't know Bryan. I suppose I would anticipate the structure within healthcare... will vary from community to community... Whether you separate pediatric and adult palliative medicine, or whether there's someone available with that kind of training or experience, it will vary with the setting, but there's surely a place for the specialized centers where there's a chance to move our understanding to a deeper level... It's the same as any other complex multifaceted, multidimensional healthcare problem.. We're talking about addressing suffering as pathophysiologic, psychodynamic, social, and existential, spiritual—and we're talking about very complex deep foundational problems.

. . .

[End of Audio]