

Bill Furdon and Maggie Bartlett January 2009

B: I'm Bill Furdon; I'm the senior case manager at the AIDS Support Group and also the director of the Food and Nutrition Program. I've been employed at the AIDS Support Group since April 1, 1989, still currently employed there where I've had a lot of different experiences.

M: I'm Maggie Bartlett and I've been a volunteer with the AIDS Support Group since 1990, I believe, and Bill was teaching a training class and I've appreciated him very much ever since. I also felt that during those... I wasn't in on the first few years, but I think I started and didn't take the class till '90 but there was a real sense of, a tremendous sense of purpose behind it with Alice's force and her, very directness, she didn't mince words and we had a lot to do and it seemed that that's the reason you were there and she...

It felt to me as if she managed it in a way that I can't picture anybody else managing at that time because she was everywhere. She'd be picking up parents who were coming to see their son, after not having seen him for a long time and be with him when he died. She would get a place for them to live and she'd give them dinner. She was an amazing force, that's what I was impressed with, but also everyone that was connected, people who weren't volunteers. There's Irene, very strong and Bill. Those are the ones that really stand out in my mind that held it together and it just felt very crucial to be a part of the town and to be with that group. It felt very ecumenical whenever you would go to a service with somebody, for one of the clients who died, you know the whole town would show up for it. In some cases, all the different ministers and the priests, the one Catholic priest would show up for it. So it was definitely a community sense that I have never felt to this extent anywhere.

B: That's very true. When I began at the Support Group, we had twelve clients and one of our first tasks, for Irene and myself was to actually open the space on 96 Bradford Street. We had gotten a space and it was going to be open to the community. We were going to open it up for the community to come and see it. So, one of the first things to open the agency, and we were hired, Irene and myself, as client advocates at that time; and we had probably about twenty-three clients that we worked with. We would set up volunteer schedules to help people and I would also do trainings at the time and I became the Director of Education and was the Director of Education for ten years just because I had a car, that was sort of my qualifications and I could drive to schools and do presentations on AIDS. And as Maggie had said, that is how I had met Maggie was through a volunteer training program that we and all the volunteers would go through. That would encompass all kinds of things. It was an amazing time and it's still is amazing time and the community really is just a very special place. I can recall... I recall setting up a... we used to have these home care schedules cause people could not be left alone. If they were disenfranchised from their families or, AIDS had such a stigma at the time, that you... you were their family and the community really came together. We would set up these schedules that would cover someone twenty four hours and we would start up with their friends and, you know, we would have friends that would fill in the schedule and we then would work with, either the VNA, and then volunteers to cover these twenty-four hour home care schedules which were amazing. They were amazing, sometimes I look at those old schedules and I see such and amazing group of people come together to make it happen. I remember doing the training. One of the trainings was the home health aide training and... turning someone in bed and things like that, and someone said, "What if we drop someone or they do that?" And I can still hear Alice going, "Well you didn't mean it." she'd say, "We'll just pick him up and we'll put him back in

bed.” She’d say, “You know, cause at least they’re home and at least they’re someplace where they want to be.” And it was so true.

We get all worried about all these other things but they wouldn’t. In putting some of these schedules together we had some of these volunteers that were trained to do these home care situations. One of them, she was very good and she wanted to work, but she was a... she was working at Napi’s at the time, she was a waitress at Napi’s, and she said, “I can’t, I need to work this shift. I have to work, I can’t take care of this client, I have to go to work on this shift, I can’t do that.” So I had another volunteer who had not taken the training course on home care, who also worked at Napi’s, so I would call up that volunteer and ask if she could work for that shift, so we could have the other one... we were covering people’s shifts back then. So there’s many, many different stories, I think. Recently at the... we were in a float in the carnival parade here in town and as I walked... I was walking down Commercial Street, we were in the float, in this parade and it’s amazing, I remember coming here on vacation so long ago and just experiencing Provincetown as this great place to be and not knowing anything about what went on in the little houses or in the community, and, as I walked down the street last year, I thought, “I’ve been in so many of these little houses and so many of these apartments, so many places I’ve been involved.” and it’s been an incredible experience. You know, I’ve been very fortunate to be let into people’s lives, especially at an important time of it. Many of the clients have given me a lot to my life and they’ve given a lot to the community as well.

M: I think that an important part for me was that one on one, that closeness. You would be through the night, you know, with one client and knowing that somebody else was coming in, but just that coverage felt really good, that nobody was ever going to be by themselves at that

particular point in their lives. I remember taking, after I finished the training course I said, "I'll do absolutely anything except drive to Boston." The next time I got a phone call it was to drive the van to Boston and I did that for ten years but I never relaxed on that trip for one minute because it was always a different sequence. You never could just start at Deaconess and go to Beth Israel, you never had a route down, you just had to wing it every time but the clients were absolutely wonderful. They were the big help all during that time.

(Catherine Russo, Director: "What was it like driving with the clients? Did you have conversations with them?")

M: Oh yeah. It was... it was wonderful. That was such a great part. Sometimes it would be such a good trip, that it would feel like we'd been away for a whole week-end.....we became so much closer in that experience. Other times, you know, sometimes it wouldn't click like that, but mostly it did. I remember one man from Texas was singing 'Up Against The Wall Red-Neck Mother' all the way home in the van and teaching everybody the words. It's a Jerry Jeff song from Texas and it was just, I don't know... that was a great experience; just the joy of that... it's a really raucous song. It just always felt good after it was over.

One of the hardest parts of the drive, I was thinking about that today, driving up here, in the winter time, during that time to be here at 7:00 AM you had to leave Eastham at 6:00 AM. That was probably the worst type of weather. I hadn't thought about that.

I remember, during the training, someone next to me said, "I've been with so many people now that have died, I've lost track of them." You know, he'd had so many friends that had died. He was also in the training. He stopped counting and at that time I decided I never wanted to ever

feel that there too many people who died that I wouldn't remember each one of them and right from the beginning I did a morning meditation where I remembered the names of everyone that I'd been with and something very special about them so it wouldn't become unbearable.

That somehow made it easier to manage and I remember, there became a large number, and what was very good... and I remember telling Bruce about this, I think... I started to write them down and I put them all down so I could... it would still be fresh in my mind and I still would meditate but not individually and I did that perhaps for about six years and once I had written it down, it felt like a big relief and it was also the best way I knew how to handle that type of continuous grief. You could never not be affected by each death, it was.... and as Bill was saying it was such an important time to be there with somebody at a very important time in their lives.

There are so many times with people who are dying that are so meaningful, just for that reason, it would be nothing that you would expect but the absolute simplest... I'll tell one story. We had Sam Demerest, her brother Bruce Demerest came here, he had AIDS, to die. She was very active as a volunteer and contributed a great deal to the group. But when her brother had had a brain operation that he hadn't wanted to have had. He didn't want it, but they wanted to do some experimenting.

That's what he said, more research, and this was done a Beth Israel, and then, when he came back, he wasn't the same. He just didn't have the same expression... ways to express himself, but he was also very close to dying at that particular point. When he first came we had a lot of time together and we joked... he started out by saying, "We WASPS don't do this so good." I said, "What do you mean?" He said, "We don't die so good." So we would be telling each other stories about why we didn't die so good. My father had been a minister and whenever a hearse pulled up by the church, everyone would come in so gloomy. I told him the story about this. I

must have been about five, at the time, and I'd walk around the church expecting that they were going to send down a note, whoever had died saying, "I made it alright." so I could slip the note to my dad and everyone could go happy. This was my idea of a good ending. Anyway, he got a kick out of that and he said "How many times did you do that?" I said, "I can remember doing it three times and I never told a soul, but nothing ever happened." The note never came down.

So he would joke about that and when he was dying, I was holding his... I kind of had my hand on his... my right hand on his left shoulder and he had the hiccups and we were trying to massage the part where you could get rid of the hiccups, right underneath here, we were taking turns doing that. His eyes were all blurred and he couldn't speak at that time and I happened to be looking at just the right time, and this is why to me, the most important thing we learn is to pay attention, his one eye just came right up at me, it was just commanding... I just looked right into it and we were transported out of that room. That's the only way I can express it and it was in a beautifully lit place where we were surrounded by dark green, I think it was probably ivy, it reminded me of a huge ivy wreath and we were together in that light. I don't know how long it lasted. I think there were other people in the room, in the far side of the room, and I don't think it could have been more than maybe a minute or a half a minute, but he took me to the place, showed me where he was going to be.

I could never have made that up... I know that. Then, I was back in the room and we were right there together and he had a smile on his face. He smiled and a tear was coming down from the eye that had just forced me to pay attention. It was just... that was Christmas Eve and he died just before the church bells started to ring at midnight and he'd been born on Christmas. So, it was just an incredible experience, but you're not looking for anything that emphatic or definite, but sometimes it comes. From that time on, I realized that everything mattered, everything, and

that paying attention was something... and he wanted to give me that gift, and he was unable to speak, as I say, he couldn't communicate any other way.

That was pretty amazing to me.....and I feel differently about death after that also.

Another client told me that his doctor told him... he asked him, "Is it going to hurt to die?" And the doctor kind of laughed and said, "Oh my son, it hurts much more to be born." And I thought, "Wow, you've been there, done that." So that kind of took the fright out of that too, for him. He seemed to be very peaceful and pretty good with it at that point. Those are just two... I sure you have

B: It's different, everyone has different stories I think. One of the things, my role there is an advocate, someone that is sort of always organizing things and making sure people's benefits are in order, their insurances, but, I think of, some of the experiences at that time, and still today. Sometimes people come to you and they're like a fifty piece puzzle and some are two thousand and you can start to work on them and hopefully they can change their life or improve. You can just about finish the puzzle and everything looks good and they'll completely rip it apart and you have to start over again. Working with young people, I used to work with senior citizens a long time ago, but working with young people at that time with the disease, the fear was always there. It was hard because that was not what my... I couldn't always join in with my feelings with the clients because they expected me to work with their insurance and organize those things. The good thing about Provincetown being such a transition town and you work with a lot of people dying, sometimes you think well they must be in Florida, on vacation,... when they're not there. I remember working with one client, in particular Peter Trout and he... it was toward the end of his life and I went in to see how everything was going and to thank him because he had tried all

these medications. He said to me, "Bill, is there anything that I could take or that is new?" Cause we were always the source of information, so it was like. "What is new? Is there anything? A trial I can be part of?" and I said, "No, no, but you have contributed so much and you will help others some day, but trying all that you've done will some day help someone." And it has and it did, you know. I thanked him too, for letting me into his life at such an important part of it. Suddenly, 616 Commercial Street was never the same. Can't walk by the White Dory without being in that room, in that bedroom, just not the same.

(Catherine Russo, Director: "What kind of problems or hassles did you have helping clients out with the state or town?")

B: Well some of the issues that was happening, going back into the early nineties, was, the town itself, had some issues around HIV. They were concerned it would affect business. Maybe people would not come to Provincetown, because it was considered this gay town and all these people with AIDS were there. So we used to hold town hall forums where we used to... we would try to do educations for people to explain to them that ... it was not going to effect it. At the time we would pay our dues to get into the different business guilds or things like that, but we wouldn't get our stuff printed so it took them a while before people eventually came around. So I think it was tough on the community at that time. But, the funny thing about it for me was, we used to go around and collect for the Art Auction every year and we would go to all the places in the town. We would go to restaurants and gift shops and everyone would contribute and we would want to acknowledge that, but some of the places would contribute but they would

not want their acknowledgment to go in the newspaper or in this. In other words, the whole community was giving, it was so special, and if everyone would just stop worrying a few minutes and just really realize that every single Portuguese, whether it was a straight, or the oil company, every single group participated. Because every person was touched, but that fear, at that time was such a... it was just such a difficult thing for people to deal with.

I remember going to a bakery; one of the bakeries in town would say, "You let me know when you need a tray of pastries for a memorial service." or "If someone needs something you tell me and I will produce two trays of pastries for you."

I'd say, "well can I thank..." "No, no, I don't want any thanks."

So those kinds of things that make the town, really, from my point of view, being an insider, really can see how very special the community has been.

M: They seem more ready now to come out and receive acknowledgment.

B: Yeah, but now is a very different time, it's just so different, but back then they didn't want their name associated with AIDS.

M: I remember working on the quilt, in the big room, and we had it all spread out, and you asked me to bring in my machine, so you could sew, and then it just got... it was huge. I remember being with a client and we were talking about the quilt and he said, "Well my parents will put in the paper that I died from something else. I know that. But I would like to have my name on the quilt." So, when he died I called his parents and asked if it would be alright if we added his name and they said, "No." But we put it on anyway because we didn't have any last

name. It was that whole stigma. I was with a client once when he received a call from his dad and it was very emotional and he said his father finally said, "I love you." He said it was much harder for him in the beginning to just realize I was gay. The fact the I was dying with AIDS wasn't the important thing, but he finally had come around. He had written him a letter, and hadn't received one. Finally his dad called him and got that out but you didn't see many parents in those days. That's why we were the family, as you just said before. Very few parents, a few mothers, do you remember Marion, I'm still in touch with Marion. Marion came. And she came from Vermont. She stuck right there through thick and thin, but she was the first mom...

B: Yeah, very rarely would the families... they would come in the end and I think that was always upsetting to see them come and clear out an apartment or clean out someone's life. I had a difficult time with one of them because she had wanted to come in. Her son had died and his partner was still alive, which was Richard Coggins, and I said, "You can't, you can't do this. You can't just take away this person's world" Yeah, we were sort of everything. I remember wheeling a.... we used to have one or two beds that were electric, which was great... rolling it down Commercial Street in August, past people, pushing it right down, right down the street. People just looking at me and I was like, "I don't care".

M: It didn't matter what anyone else was thinking at that point because everything you were doing had a purpose, so you weren't worried about what anyone was thinking.

(Catherine Russo, Director: "Did you get a lot of calls about how to deal with this, from the community?")

B: Well, sometimes we would get calls on that. People were very fearful. People were afraid. They were afraid... there were several different types of calls... some calls we would receive in the agency would be about someone being fearful about being exposed. Some were newly diagnosed people, people that had just gotten... and they were angry, they were angry that someone had done this to them, they had felt that... so there were all kinds of emotional kinds of things the Support Group did. The Support Group is... we were not just there to help people with death and dying, that was a big role at that time... but, as we still do today, we really helped people along the path, get them through all the tough spots, especially like paperwork and bureaucracy, which I love. I love to put paperwork together, help people and just move them along the way, just get them over the bump, and you just go live your life until the next paperwork problem or what not comes through. It's challenging for me but...

(Catherine Russo, Director: "Can you talk about the trainings?")

B: Well, Maggie was one of them that went through one of my trainings. What we would try to do, at an initial training... and you (Maggie) can talk some more about it too... we would separate the trainings up. Sometimes they were six or seven weeks long. Part of the idea with the training too was to get a group of volunteers together that would also be able to support themselves during that training time, because they would need each other to rely upon each other within their own group. The trainings would be separated in several ways. We would do like an AIDS 101. Then we would really talk about where people were at and their baggage. Cause some people would want to come and volunteer, but they really have to learn to leave that

outside their doors, because they were stepping into people's lives.

We were there to assist, we were not there to direct. We were there to help with someone's life, not tell them what we thought they should be doing with it, which is tricky to do in some cases. Some people wanted to do what they wanted to do. We used to have a nurse that would do a training on helping people move in bed and changing an occupied bed. We had an acupuncturist talking about alternative therapies, cause lots of clients were on alternative therapies, which people thought were crazy. I said, "You know what, if this helps someone we cannot....you know, we can't make these judgment calls."

M: The panel... we had a panel of four of the clients. I remember Alice getting up after they had left and said, "They are all very angry." They were all very angry and she said that and it was very helpful for all of us to realize, you know, like, "Take it like it is." without any judgment on that. This particular panel, I don't know if she chose them or you did, but this particular panel they were all very angry.

But she said that... they were angry about having HIV, having AIDS, having all the stigmas that were attached to it. Very upset at being disowned by society and being forced to come to a place that would receive them... leave their homes to come to P-town, where they could be cared for. So, there was an awful lot of that but she explained that in the very...

(Catherine Russo, Director: "Can you talk about Provincetown being a destination for people?")

B: Provincetown really was the end of the line for some people and what a great place to be and thank God that we had such a great group of people to help out to do this.

M: And San Francisco had one, but I think we were the only two...

B: Well we had one of the largest rural populations of people with HIV in the country, in fact we still do, per capita, if you look at our population here, Provincetown has one of the largest per capita. So what would happen is that people would... the city of Boston was starting to become overwhelmed. With AIDS Action, lots of clients were trying to go to get certain assistance and help for them. We would do a little bit more kinds personal types of care at that time and also try to help people get on disability, help people get health insurance. People would have, people would suddenly become... what would happen is you weren't... there wasn't all this pretesting and there wasn't all this like pre-screening, usually what would happen is that people would get sick, they would have pneumonia, they'd land in the hospital with no t-cells, exhausted and sick. They didn't know how to apply for health insurance, get on disability, how they were going to pay their bills, how all those kind of things were going to happen. Who was going to take care of them during their recovery. Those kinds of things began at that time. You would be hit with pneumonia and usually by your third bout of pneumonia you were dead. So, people had to put a lot of things in perspective, because we had no medications at that time or very few of them. Medications we had prolonged people's lives to get them in order and to do some of the things that they needed to do.

(Catherine Russo, Director: "And people's families did not help?")

B: No, and part of that was fear and just many different things.

M: That's why Alice and the group was so important because that would all be taken care of... it really was along with so many other things...

B: Well, Alice always gave you such a wonderful feeling of "not to worry about it - that you were doing the best you could". She always made you feel... like with me, I started working there when I was twenty three years old and I thought, I was the youngest member of this team, and I said, "Alice, why do you want me here?" She goes, "You are youthful, you have ideas, you'll come up with all kinds of solutions." She says, "I'm an old woman, I can come up with some things but I need your youth to help figure out alternatives." I didn't quite understand what she was talking about at the time, now I do. One of the things she loved was; Guy used to smoke all of the time and he used to dose off smoking and he was very sick and he was going to burn his house down. So we set up this cigarette thing. I had poured this ashtray with a big thing on it that he could suck this cigarette down from in bed and it would burn out into the tray... ashtray; kept burning that out. Alice would say, "Look at that."

M: The training gave you the confidence to go out and as Alice would say, "Now just go do it. That's where you're really going to learn something. Just go do it." One day when I went to pick somebody up, he had tried to commit suicide. I got myself in the apartment and called 911 and then I called the Support Group and I said, "Now, what should I do?" Because I thought I should follow him to the hospital but I had two other people to pick up and she said, "Get on with it, get on with it." "Just move, on, you're going to be late." Then when I got back that day she says, "Back so soon? Pretty good for an old lady." I was in my fifties at the time so I didn't take it... that was pretty funny at the time, I felt like "Who you calling an old lady?" I don't

think I ever really got fresh with her, she was just that... that's her character. You couldn't take yourself too seriously that's the main thing, I think, with Alice. She didn't have any patience for anyone who took themselves too seriously.

B: She was so special, very special. Yup, she used to say, "You know more than most people do." And she was right, we did.