

**Adelle/Joe Interview
(21:00)**

1
2 Q: What was it like when you first found out Adelle needed a transplant.
3 Joe: Before we found out she needed a transplant we were informed that she
4 was dying. And it took a while for that to sink in, they didn't actually use the
5 "D" word. And I guess maybe a couple years before she had her
6 transplant it really sunk in and I was devastated.
7 Adelle: Well the doctor actually didn't say that I could have a transplant. He said
8 that I was not a candidate, um that basically that I should get my affairs in
9 order and we should go and get a plot and wait for the time to come. It
10 wasn't until we met some people in our support group that we found out
11 through the newspaper that there was even a transplant available, the
12 idea didn't come from our doctor it came from our support group. And in
13 fact I was not a bit interested I was so sick. I just wanted to go, I was ready
14 to die. I had given up and Joe wasn't ready to let me go that's for sure.
15 Joe: We had no idea. We heard about liver transplants, we knew so little about
16 it. And from what I recall you had about a 30% chance, that's where it was
17 at one time. But then we saw an article in the newspaper about people
18 who had transplants and called and found where a support group was
19 and I showed up there, and wow the enthusiasm of everyone there and
20 the help. And they helped us within a very short time find another doctor
21 and we to make a long story short about five months after getting involved
22 with the group she had a new liver.
23 Adelle: They got me the transplant list right away. As soon as I got to UCLA Dr.
24 Goldstein took one look at me and said, "You need a transplant", and it
25 went very smoothly from then. I'll never forget the moment we got the call.
26 It was like I can't believe this you know. All the way down the drive to the
27 hospital we were so quiet, we were so peaceful. I remember saying to
28 Joe you know it's like if it had been our last drive, it might have been our
29 last few minutes together and what is it you say to each other in that
30 moment when you know this could be the end of everything. Because my
31 chance of survival was you know, if I didn't get the transplant I wouldn't
32 survive. And I looked at him and I said, "Honey I'm very at peace. It's a
33 win-win situation if I don't make it I'm in Jesus' arms. If I do make it I'm
34 back in your arms. And so I was very very peaceful when it came time for
35 me to actually go in for the transplant.
36 Joe: I was very optimistic. Everything was going to go smoothly I knew that.
37 Adelle: He didn't call anybody. He didn't call any of our friends or anything. He
38 spent the entire time in the waiting room all by himself. He just was very
39 confident. He didn't really feel like he needed any support or anything.
40 And it was kind of like afterwards he called everybody and said, "Hey
41 guess what? Adelle's going to live". And um I remember when I woke up
42 in ICU I felt like a different person, and from that moment on I have never
43 had a minute of depression. I have never really been sick again. I have

44 been on a high for life. And I called him in ICU, he had finally tried to get
45 some sleep after being awake for...

46 Joe: They assured me I could sleep to noon before she would be out of the
47 operation.

48 Adelle: ...hours and hours and I woke up and I said, "I've gotta call Joe. I've gotta
49 call Joe". And I got him on the phone and, "Hello" (sounding groggy). "Hi,
50 I'm alive!". And I think I've been doing that to him ever since.

51 Joe: Oh yes.

52 Q: What were you thinking when she was on the gurney ready to be wheeled
53 into the operating room?

54 Joe: I just was very confident that everything will go well. And uh God didn't
55 bring us this far along to have any tragedy occur. And so I was fully
56 confident that she would be fine, and sure enough her transplant went like
57 clockwork. Uh six hours and they were done, like a textbook case.

58 Q: What was it like after the transplant?

59 Adelle: It was wonderful, I was home in ten days. The day I came home from the
60 hospital I walked up the stairs to my bedroom. They said I wouldn't be
61 able to do that.

62 Joe: They weren't very happy about you...

63 Adelle: They weren't real happy...

64 Joe: ... without help from anyone.

65 Adelle: But I mean I've really been sailing basically every since. When you have
66 been really really sick and you have been dying there is nothing better than
67 living. I am so thrilled to have had all these snatches of moments of time
68 with my family that I never would have been able to have before. The
69 things that we have done in the last few years I couldn't do before. And I
70 am so excited because I have three wonderful grandchildren that I have
71 been able to invest time and love and nurturing and energy into. I think
72 they'll have memories of their grandmother that they'll always have now.
73 Not a memory of a grandmother in a sickbed. They'll have a memory of a
74 grandmother running with them in the ocean.

75 Joe: Well just about two months ago she was having pictures taken and good
76 old grandma here she takes her shoes off and the next thing you know
77 she has the kids in the ocean, the waves are coming in. The kids were
78 upset at you.

79 Adelle: Yeah, they were. They had the kids all dressed up and grandma got them
80 all wet. That's OK. We've taken lots of trips, we travel. We do things now
81 that I never thought I'd ever do.

82 Q: One thing that struck me earlier about what you said about the lack of
83 information that was available to you.

84 Joe: Well prior to finding out about the support group we were desperate. I was
85 desperate. And we, for example, took her to an alternative doctor, although
86 he never guaranteed he could cure her, he never said that, but tried to
87 make her more comfortable.

88 Adelle: We spent thousands of dollars...

89 Joe: Oh boy!

90 Adelle: ... in alternative medicine.

91 J: Yeah, and he was saying you don't want a transplant. He made it sound
92 like it was really a bad thing and you gotta take drugs the rest of your life
93 and everything, and it's kind of negative you know. But we found it not to
94 be that way at all. I mean what's the big deal about taking, you know eight
95 o'clock in the morning and eight o'clock at night she takes a couple pills.
96 Well I take my vitamins, what's the difference you know? And she's alive,
97 she's doing well, and it's wonderful.

98 Adelle: I think the information that we had was that the immunosuppressants
99 were going to be horrible, that there were so many side effects that the
100 quality of life was going to be so limited. And that was very fearful to me
101 because my quality of life was already so tragically limited that I didn't want
102 any more grief. I didn't want to live sick any longer. And I was very scared
103 of what this monster was that I didn't understand. And I thought maybe I
104 might not be able to handle it because when they sit down and they talk to
105 you about the protocol and how important following all these protocols
106 were, it was very very scary at first. But having a support group and having,
107 especially a wonderful caregiver, but wonderful personnel. And the
108 doctors and the nurses were so informative and helpful that when it came
109 time everything was smooth. It was all our fears before of not know. Not
110 knowing where to go for help. We spent years, absolutely years, in a pit of
111 misinformation and not understanding. Not knowing how to
112 communicate. It's very very difficult to have a sick member of your family.
113 When your wife is sick and the children, everybody suffers, and it's not an
114 easy thing emotionally, physically, all the things that go on. We didn't
115 know where to go for help.

116 Q: Did you have any side effects at all to the drugs?

117 Adelle: For a few months I had high blood pressure. That went away. I did
118 become diabetic. I was not diabetic prior to the surgery. That's a minor
119 thing. Some people might say it's a major thing. Hey, I'm alive. I'm
120 diabetic, there's a lot of diabetics out there. There's thousands and
121 thousands of diabetics. I would rather be a living diabetic. There's a
122 tradeoff here. I have had a lot of problems with my weight. I've gained a
123 lot of weight since my transplant. But on the alternative I'm happy, I'm
124 alive, and I'm healthy. And I don't see that I have any real side effects that
125 have given me any reason that I can't live a full and productive life.

126 Q: If you could do something to help somebody have the information that they
127 need. You found yourselves in that dark pit. You know what we're trying to
128 do here. How does that relate to your experience and how would
129 something like that help you?

130 Adelle: Well I think the Internet is an incredible vehicle. Since my transplant I have
131 been able to get on the Internet and find out a lot of information and I have
132 found support groups, and I have found it to be very wonderful for me. It
133 would have been great had I had been able to find this information prior
134 when I was so ill. I think that this is absolutely phenomenal to realize that
135 the people now who are looking for information would be able to find it.

136 Joe: And furthermore she communicates with people on the Internet on a daily
137 basis. She has a whole group out there that she's throwing things back

138 and forth on, and she's helping a lot of people through that. And also
139 sometimes people call, you can help others. Good dear friends of ours,
140 his wife ended up with the same condition that Adelle had and we were
141 able to be supporting to both of them during their illness.

142 Adelle: I think you can't have too much information. I think that our biggest fear
143 was not having information, not knowing. I'm the kind of person that
144 needs to know. I want to know everything. I want to know all of it. And I
145 was very hungry for information and I think most people are that way. And
146 I'm really excited to know that people can log on and get information and
147 get help.

148 Q: What we're doing is to hook up the Internet with video, with a DVD.

149 Joe: Again our biggest problem was lack of information. Like I said earlier my
150 knowledge of transplants was the chances were against you surviving it. I
151 thought it was 30 percent and found it's in the high 90's and all. If we had
152 that information I think we would have been a lot more enthusiastic about
153 going forward. But that was the problem, lack of information.

154 Adelle: Well doctors aren't very forthcoming it seems...

155 Joe: Well that's for sure.

156 Adelle: ...when you're spending five minutes with them it seems, when you are
157 terminally ill, and they give you this prognosis for your life. You come
158 home and your head is just spinning and I think it would be incredibly
159 wonderful to be able to sit down and have this vehicle of information. And
160 that just thrills me. I would love to be able to go backwards and I can
161 visualize myself finding that information. I think it would have been a lot
162 easier journey for us.

163 Joe: We did not get the information from the doctors. I mean it was like closed.
164 I don't know if it's because of HMO, we're not rich, we're not famous you
165 know. We just had no information there. In fact we were very discouraged
166 by the doctor. So we found that we had to take the lead ourselves and look
167 out for ourselves because the doctors weren't going to do it.

168 Q: So if you had the ability to talk to people like yourselves and hook you up to
169 the Internet how would that have changed your lives?

170 Joe: We were so hungry for information and we didn't really have it. We got little
171 bits and pieces here and there. And to be able to have that available to us,
172 we needed that at the time, wow it would have been so helpful. There's
173 always questions and things that you continue to have.

174 Adelle: I think that one of the things that a lot of people don't realize that when you
175 are really really sick your brain is also affected. Your ability to understand
176 and comprehend is compromised. And sometimes the sound bites that
177 you get from your doctors don't always register. The ability to be able to
178 plug something in and to be able to see it maybe more than once, to
179 review it over and over, to have the information just right there for you
180 whenever you would want it. Like if it's at one in the morning or if it's at two
181 in the afternoon when you want it, when you need it and you're maybe at
182 that point you're cognizant and able to understand during this brief period
183 right now I can maybe focus on what it is that I need to understand about

184 my health. That's wonderful. The availability on a 24-hour basis, seven
185 days a week, any time you might need it.

186 Joe: Then to hear real people, actually see faces, and real people talking to you
187 who have been there, you know it's not just something out of a book even
188 though books are very helpful, and a little article here and there is very
189 helpful. But just having people share with you. And instead of just one or
190 two people, hearing it from lots of different people, would be really helpful.

191 Adelle: I think when you are going through something very catastrophic you are
192 very alone. You are very isolated. It's so scary. And I think that the more
193 you can be plugged in to something that is informing you but also the
194 ability to see people, as Joe was saying, I think would have been so
195 comforting to me.

196 Joe: In our case we were fortunate because the support group met just a half
197 hour from our home. But think about how many people that don't have a
198 local support group. And how do you even find a support group?
199 Something like this might even be of help in that sense too.

200 Adelle: Well I wasn't even healthy enough to even go. I mean the support group
201 met at the same time every week but Joe would have to go often without
202 me. I was not healthy enough to even get dressed. And sometimes I can
203 remember getting dressed and not being able to leave the house.

204 Joe: And then sometimes I'd leave early because your batteries had run down.

205 Adelle: Finally I'd get to the meeting and I'd sit there and I'd be so grateful that I
206 got there, and I'd have to go home. And I think that happens sometimes
207 with people having to go out to get help. Because when you are really ill
208 you can't just do that. But if you've got the availability of your computer and
209 the Internet and you can have help come to you, I just get goose bumps
210 just thinking about it. I just think it's an incredibly wonderful idea.

211 Q: What was the toughest part of the whole process for you?

212 Joe: The toughest part for me, when it finally sunk into my head, she kept trying
213 to tell me that she was dying. That did not register because I have the
214 attitude that I can fix anything. But this is something that I could not fix.
215 And that left me so helpless.

216 Adelle: He kind of thought that if I took vitamins and if I took walks with him and I
217 had a healthy attitude, and I thought healthy and acted healthy that I would
218 be healthy. And it took an awful long time for him to really really
219 understand that I was dying right in front of him. He did not comprehend,
220 because he was busy in his own life. And I wasn't one to go around and
221 whine. I just wanted to go to bed. And to him having a wife in bed for
222 many years was very very depressing. It's very devastating. We all have
223 our own realities at different periods. And I think that's very very hard, the
224 loneliness of it, the isolation of dying is I think the worst. I don't know if I
225 really ever believed that I'd get a transplant. To be perfectly honest I didn't
226 think I'd be lucky enough. I was prepared to die. I thought I would die. I
227 don't know if I ever shared that with my family because I think that they held
228 out hope that I would. But I, when I got that call, I absolutely, if I could have,
229 I would have done handsprings. I'll never forget the phone call. It was like
230 I got a second chance and I never thought that I'd ever get that. And I don't

231 dwell on the devastation any longer. There is so much to be excited about.
232 There's, um the hardest part for me at this point right now is finding
233 enough time in the day to do all the things that I want to do. I'm just so
234 grateful to my family for sticking with me, for hanging in there and loving
235 me, and just the amount of people that go into supporting people that are
236 ill. I don't think, I don't know how people could survive without a support
237 group and without a faith in God. I think that beyond anything else, my faith
238 in God has sustained me. I have no fear about where I'm going. I have
239 great peace that if I died tomorrow I know that I've had a wonderful time.
240 I'm just very grateful for all the time that I've been given. It's just a gift.
241 Joe: And you're my gift.
