THERAPEUTIC SUPPORT GROUPS

SPIEGEL DAVID

SPIEGEL, M.D., is Professor of Psychiatry and Behavioral Sciences and Director of the Psychosocial Treatment Laboratory at Stanford University School of Medicine. In 1989 Dr. SPIEGEL , published a landmark study on the effect of psychosocial treatment on patients with metastatic breast cancer. Also known for his work in hypnosis as treatment for pain, he is coauthor, with his father, Dr. Herbert SPIEGEL, of *Trance and Treatment: Clinical Uses of Hypnosis*.

MOYERS: When I read about your study, it just seemed so commonsensical that people who get their feelings out in the open, who have the support of loving friends and family, who are able to distract themselves from pain, and who know that they're not unique in suffering or alone in dying are going to be happier and more hopeful, and therefore better able to cope with disease. I can certainly see that psychologically, but I have a hard time understanding what it means physically, and, therefore, how it helps to prolong life.

SPIEGEL : We don't know the answer, physically. But if thinking about death elicits a kind of fight-or-flight reaction, and you're in a chronic, unmodulated state of discomfort, your body is busy handling all these signals, and

▽158 it becomes stressed. Whereas, if you get to the point where you can say "I don't like the idea of dying, and it will sadden me that I can't do what I've done in the world and that I will not be with the people I love and care about"---then you're more in control of your mental state, and your body is not responding in that same helpless aroused way. We think that may have some impact on how the resources of the body are available to do what it has to do to fight disease. Now that's only a theory at the point, but we think that may be what's going on.

MOYERS : So my mind is summoning my body to a different response than might have given on its own without the conscious effort on my part.

SPIEGEL: That's a good way to put it. If you can't control whether or not you die you can at least control how you live and how your body is handling the stressor that you're facing.

MOYERS : How important is self-hypnosis in all of this?

SPIEGEL : Self-hypnosis is very important as one highly structured way of regulating your inner states. As part of the treatment, we end each group with a self-hypnosis

1 exercise. Hypnosis is really just a state of focused concentration. It's like being so
2 absorbed in a good novel that you forget that you're reading a book, and you just get
3 caught up in the story. We couple that with learning to control the way your body
4 responds. So for example right now you have sensations in the part of your back that is
5 touching the chair, but until I mentioned it, you probably weren't aware of it. We call
6 that "dissociation ." You've put those sensations out of your conscious awareness. If you
7 can do that with the chair, you can do it with pain. So people who are focused on one
8 thing in hypnosis can often filter out many uncomfortable sensations. They can learn to
9 transform the feeling into some other feeling, or jus pay attention to a different part of
10 their body. And they can also learn to face problem that worries them without having
11 their body react so much to it. For example, we teach them to imagine that their bodies
12 are floating in a hot tub or floating in space, feeling comfortable, while on an imaginary
13 screen they're dealing with some issue that concerns them.
14 MOYERS : So hypnosis is not a form of black magic.
15 SPIEGEL : Absolutely not. It's an everyday form of highly focused concentration.
16 MOYERS : Is it like meditation?
17 SPIEGEL : There's some overlap with meditation. The mediators would say that in
18 meditation you concentrate on nothing, and in hypnosis you focus on something. There's
19 also a difference in the ceremonial ritual that surrounds it. But anything that gets you
20 into a state where you're mentally alert while physically relaxed has elements of a
21 hypnotic or trancelike state to it.
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24 MOYERS : Even though it's hypnosis, it's conscious effort to control part of what's
25 happening, right?
26 SPIEGEL: Yes, absolutely
27 MOYERS : It increases my control even though I'm a victim of disease.
28 SPIEGEL : One of the misconceptions about hypnosis is that it's a state where you lose
29 all control. It is true that in a hypnotic state you may be more receptive to input from
30 other peop1e. But hypnosis is really a means of heightening the way you control and
31 regulate your inner states'. You can put aside distracting sounds or feelings and
32 enhance your ability to focus on what you want to at the moment. After focusing on
33 something for a set period of time, you're able to put it aside. The ability to put
34 something aside is as helpful as the ability to focus while you're in the hypnotic state.
35 MOYERS : Did the women in the control group, who didn't get special treatment, report
36 more pain than the others?

1 SPIEGEL: Yes. We had all the women rate their pain at intervals every four months.
2 Over the initial year, women in the control sample reported that their pain had
3 doubled-from a two to a four on the ten-point scale. But the group that was trained in
4 self-hypnosis reported a slight decrease in pain, so that at the end of the year their
5 average pain ratings were less than two.
6 MOYERS : What's really going on in self-hypnosis? How does it work?
7 SPIEGEL : Hypnosis seems to be a way of filtering out information you really don't
8 want to have. We've done some research with a mild electric shock in which we've told a
9 hypnotized subject, "Your hand is in ice water." In that condition the brain does not
10 respond as much to the electric signal as it would if you were simply paying attention to
11 it. In fact, when hypnotized people are told that the electric shock is a really pleasant,
12 interesting sensation, the brain exhibits a stronger response to the signal than it would
13 ordinarily. Hypnosis is like an amplifier. You have the same signal coming in from your
14 compact disc player, but if you turn the volume up, you'll hear a lot more sound than if
15 you turn it down. Hypnosis seems to help people gain greater control over whether their
16 brain amplifies signals like pain.
17 MOYERS : So you turn down the amplifiers that are bringing in the unwanted noise.
18 SPIEGEL : That's right. You have to pay attention to pain for it to hurt. You can lessen
19 the pain either by turning down the pain input or by turning up the attention that you
20 pay to other signals in your body or other thoughts or images.
21 MOYERS : Can anyone learn how to do this-even a journalist?
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24 SPIEGEL. : Even a journalist like you could learn it, but you would have to suspend
25 some of that critical judgment you use so well. Probably eighty percent of the general
26 population is capable of using hypnosis to some degree. About ten percent can use it to a
27 rather profound extreme. There are even some patients with very severe pain who can
28 learn to control that pain primarily with constant use of self-hypnosis.
29 MOY E R S : Listening to you makes me think I might be able to do something like
30 self-hypnosis and be able to face pain better than I thought I could-or even death. But
31 what have you learned about the importance of the doctor and patient relationship in all
32 this?
33 SPIEGEL: It has deepened my appreciation for what it means to be a doctor and
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36 for what patients need. In our medical training we tend to focus exc1usively on the

1 technical aspects of what we do:-surgery, chemotherapy, and so on. But I feel more
2 strongly than ever that the doctor's role is to help patients cope with all aspects of what
3 it means to be sick and to face limitations in life. The best medical care must always
4 involve attention not only to the physical treatments, but also to the way the patient is
5 coping with them. We must help patients understand what's happening to them and
6 help them mobilize support from family and friends. Just a little bit of caring goes a
7 long way. It doesn't have to be an elaborate thing. Just saying. "I'm really sorry this
8 happened to you, and if you need help, I'll always be there to help you" makes a
9 tremendous difference to patients. Doctors need to know that.
10 MOYERS : Ironically, your skill in caring can be seen as a flaw in your study. People
11 could say, "David SPIEGEL is such a good psychiatrist and such a good leader of this
12 group. But, unfortunately, there are not a lot like him." You may be raising hopes that
13 other people can benefit from this kind of group support when in fact you can't replicate
14 the man who makes the program work.
15 SPIEGEL : Well, I'm honored, but I really don't think it depends on me, It's the
16 combination of the approach that we take, which is teachable and learnable, and what
17 the patients do for one another. I simply try to provide a setting in which I show my
18 caring for the patients, and I help structure what they talk about. I didn't run all the
19 groups in our study-and there were no differences in survival time for the groups that
20 were run by other health professionals. I don't have any corner on the market of human
21 caring. There are lots of very ' good, caring professionals' who can learn to do this if
22 they're willing to unlearn certain parts of their medical training. A lot of doctors, for
23 example, think that crying should be treated like bleeding---just stop it at all costs. But
24 I tell the medical students at Stanford that if you see somebody crying, don't just do
25 something, stand there. Be with them for a few minutes, and let them know that you're
26 open to their discomfort. It doesn't take a lot of sophistication. It just takes knowing
27 what to do in a difficult situation.
28 MOYERS : But why do you use psychotherapy? Why not offer a simple support group?
29 SPIEGEL : While I'm a great believer in self-help groups, the kind of support that
30 someone who's dealing with a serious illness needs goes beyond a general sense of "I like
31 you, and you like me, and here's the latest treatment" for this or that. It means being
32 able to tolerate the very strong feelings that arise when people have to give up their
33 ability to do things. Grieving for people you have cared about who have died, and facing
34 your own fears of dying, and handling pain-those kinds of issues require focused
35 attention. They require a serious effort to allow people to share what they're feeling
36 inside so that they feel comfort and supported when they die. That goes beyond the

1 usual notion of support groups.
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4 MOYERS：You're doing this at Stanford Medical School, a fine institution of medical
5 training. Are people out there going to think. "Well, that's wonderful for a select group of
6 people, but I'll never have access to this"?
7 SPIEGEL：I certainly hope that's not the case. You know, from the perspective of health
8 care costs and implementation, group support is ridiculously inexpensive. It costs
9 virtually nothing. You have to pay a professional salary, and you need a meeting room,
10 and that's it. If you compare the cost of that to even a minor surgical procedure, it's
11 trivial. So what we need to do is to get ourselves back in balance so that helping a
12 patient deal with illness through a support group of one kind or another considered a
13 routine, necessary part of health care, just like all the other aspects o health care. I can
14 assure you that support groups are far easier to do and far less expensive than many
15 things that we do in health care today.
16 MOYERS：I believe that, but when you have a group of strangers who have in common
17 only their inevitable encounter with death as a result of cancer, it must be hard to get
18 them to open up to each other. How do you do it?
19 SPIEGEL：Actually it's not as difficult as you might think, because we're providing for
20 them something that they know they desperately need. I've been struck by
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22 ▽the fact that if you simply keep the focus on the important issues, these people quickly
23 come to care about one another very deeply. For example, one woman m one of the
24 groups had to go in for a major surgical procedure, and one of the women she'd met in
25 the support group just a few weeks before came to see her in the hospital. When the
26 patient returned to our group, she said to the woman who'd come to see her, "Your visit
27 meant more to me than all the other visits I had. You really know what I'm going
28 through." That sense of being in the same boat is really a very powerful thing when
29 you're dealing with something that's difficult, so I find that it's ht think to get people
30 like this to open up to one another, a lot easier than you might think to get people like
31 this to open up to one another.
32 MOYERS：When the women come together, exactly what are you trying to make
33 happen.
34 SPIEGEL：I'm trying to create an atmosphere in which we talk about the hard stuff not
35 the easy stuff. I'm looking for signs of emotion, for someone beginning to look like she
36 wants to cry, or someone who is feeling worried about something but not quite able yet

1 to talk about it. I try to set it up so that the deeper concerns are the ones that we focus
2 on in the group. And I also try to keep the discussion focused on what's going on in the
3 room. It's very tempting to go into an interesting story about what happened to
4 so-and-so, or whatever. But when that happens, the emotions drain out of the room. I
5 try to keep the focus of attention on what's going on right now: what issues are you
6 dealing with right here, and how can we help you deal with them?
7 MOYERS : These are women who, in many cases, probably haven't had psychotherapy.
8 They're facing death, they're grieving, they're in pain, and they're feeling isolated. It
9 can't be an easy thing to try to get them to open up and express their feelings to
10 strangers.
11 SPIEGEL : At first, of course, there's the usual reticence to talk about something that
12 you haven't talked about with anyone else, in a room with people you don't know well.
13 So I try to focus on their common experience, the things that bring them together rather
14 than separate them.
15 MOYERS : Like what?
16 SPIEGEL : Like the difficulty some of the women have talking with their husbands
17 about how scared they are. They'll tell their husbands, "You know, I'm really frightened
18 about this physical exam that I have coming up." And the husband will "Oh, don't make
19 yourself sad, because you'll just let the cancer get worse." or something like that. The
20 woman takes it as a message that her husband doesn't want to deal with it anymore.
21 Then another woman in the room will say, "You know, my husband was the same way,
22 but I said to him one day, 'Well, you're going to hear me
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24 ▽165worry whether I like it or not.'" And the first woman will say, “Maybe I ought to
25 try that," or, "I don’t know if I can get away with it, but . . .." You begin to get the sense
26 that it isn't "your" problem, it's "our" problem. That happens when people feel that they
27 can take the risk of talking about what they're really scared about. I'm also very careful
28 to make sure that they get responded to when they do talk. If they say, “I was really
29 scared when I woke up this morning and realized I had to have another bone scan, you
30 respond to it: "You must have felt really terrible. What do you do to help yourself handle
31 those fears?"
32 MOYERS : What does responding in that way for them?
33 SPIEGEL : First of all, it normalizes the reaction. People sometimes tell themselves,
34 "Well, a normal person would handle this fine. I'm the only one who's really scared like
35 this. I'm being silly. It's just a procedure." But expressing their fear in the group helps
36 them feel that their strong emotional reaction to a tough situation is a perfectly normal

1 thing. It also reminds them that they're not the only person in the world who has this
2 kind of suffering. When you get seriously ill, you tend to think there's this normal,
3 healthy, happy world out there, and everybody else is just trotting along, doing their
4 thing, and here I am, miserable and scared to death. They find out that other members
5 of the group are fighting their own demons as well. And seeing that becomes a way of
6 not feeling s o removed from the course of human life
7 MOYERS : Do you have a strategy for making this happen, or do you improvise?
8 SPIEGEL : The strategy is basically to try to draw as many people as possible into
9 discussing the common theme and sharing parallel experiences so that the problem
10 becomes a group problem rather than an isolated individual problem.
11 MOYERS : What do you do about the woman who wants to deny the experience of
12 illness and who just wants to get fixed and go home?
13 SPIEGEL : I gent1y, and sometimes not so gently, challenge the denial. Usually, if
14 somebody really wants to deny her illness, the issues don't come up. If they bring up
15 issues, they're usually saying. "I'm struggling with this internally, and part of me wants
16 not to deal with it, and part of me knows that. I have to." So when they say. "Oh, there's
17 no point talking about this." I'll try to find some hook: "Well, look, it may seem that this
18 isn't very helpful, but you mentioned that it's been on your mind for the last week, and
19 you've had trouble doing your work because you keep thinking about this. So maybe
20 that's your way of telling yourself you've got to do something about it." I'll try to find a
21 way to suggest that they need to deal with it in a more direct fashion. There was a
22 woman in the group who was rather reluctant to tell other people that she had cancer.
23 That was her way of making it not real----you know. If other
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26 people don't know about it, somehow it isn't really happening. But as she talked, it came
27 out that most people probably already knew she had cancer. What she was really doing
28 was saying to those people, "I can't talk about this with you." I told her, "Look, they
29 know about it. You're just telling them not to discuss it with you." So she began to let the
30 barriers down and to talk a little more about what was going on. When she did, she
31 discovered that it was easier for her to talk with her friends, not harder if she said
32 "Okay, this is something we can discuss openly."
33 MOYERS : You allowed her to let the barriers down-but don't you sometimes have to
34 tear down their defenses?
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1 SPIEGEL : Well, I'm a great respecter of defenses. I'm quite willing to say directly
2 ('Look, I don't see it this way. It sounds to me like so-and-so knows you've got cancer
3 even though you're not talking about it." Now they're free to disagree with me. I can't
4 make people do anything, but I can give them a push in a direction. Also. ¥'hat really
5 helps in the group is that I'm not the only one saying, "Handle this differently " I can
6 turn to someone else in the group and ask, "What happened when you did this?" You get
7 the shared experience of the group. Also, when I turn to members of the group and say,
8 "I feel so much closer to you now, knowing what you've been going through," that's very
9 immediate. It's not preaching at them. It's a kind of understanding and caring we can
10 feel in the room. And that can be a powerful way of teaching.
11 MOYERS : How do you know when the group is coming together and beginning to work?
12 SPIEGEL : The firs t thing I notice is that there's more going on than I can figure out.
13 When a good group is really rolling, there are a number of very important issues, and I
14 can't quite manage them all. Secondly the discussion is more or less evenly distributed
15 around the room. It isn't one or two people giving a monologue. It's everybody chiming
16 in with some experience. Third, there's a lot of emotion in the room. People may be
17 crying, or they may be laughing, but there isn't a flat-stiff empty kind of feeling. Fourth,
18 there's almost a palpable sense of caring. You just have a sense of being together in an
19 intimate way, in which _you really care about what happens to the people in the room,
20 and they seem to care about you. That caring grows over time as people share what
21 they're going through and develop a history of helping one another. In the beginning, a
22 group can be somewhat formal. People tend to overrepresent their resources and how
23 well they're coping. They say "Well you know, I do like having cancer, but. so-and-so
24 comes and cooks meals, and so-and-so else comes and takes me out for a walk, and
25 everything is really just wonderful. I've got more support than I know what to do with,"
26 and so on. They present themselves as though they had it in hand, and there weren't
27 any big problems, really. But over time they begin to admit that they need help dealing
28 with this illness. They don't quite have it all in hand as much as they said they did in
29 the beginning.
30 MOYERS: I've known men for whom bravado is the chief resource they cal] on when
31 they hear this kind of news.
32 S P I E C. E L : Absolutely. Some men, when they start having chest pains with a heart
33 attack get down on the floor or and do push ups to prove to themselves that it's not
34 happening.
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MOYERS: A member of your group, Debbie, recently died. How did the other women react?
SPIEGEL : I think there were a number of complex things going on. They were frightened. No doubt one part of what they were ' feeling was "There but for the grace of God go l. We have the same illness. She died, and I'm going to die." At one level it was very upsetting. They missed her, and they felt unfinished. They were sort of angry-"Why didn't I say this to her? Why didn't I say that to he "' Also they were valuing what they had gotten from her. I think it forced some of them to reorder priorities in their own lives, to say, "You never know when it can happen, so if I'm going to do something that I want to do, I'd better do it now, while I can."
MOYERS : What happened to the group as a group after Debbie died?
SPIEGEL : I think the group began to become a much more coherent unit. We were people with a common history, and part of that history was that we had lost Debbie, and we had grieved her loss together. There was a sense that it was very important to be informed right away because we were members of a unit who all deserved to know what was happening with any member of it. The group came to feel much more strongly that there was an understood commitment and caring among them. Ironically, there's something reassuring about grieving losses. When we spend time mourning the death of someone we knew and cared about, it's also a message to us that when our time comes, we will not slip away unnoticed, but that we, too, will be grieved and cared about and missed. That's reassuring because many of us have an anxious fantasy; as we think about our own nonexistence, that the world will roll on just fine without us. Somebody will throw a flower on our grave, and then we'll be ignored. That can make us very frightened about the prospect of dying. But seeing that what we do is appreciated and cherished by the people we care about makes dying less frightening than it otherwise would be.
MOYERS : You bring the patient's family in when you can. Why do you do that? Isn't this hard on them?
SPIEGEL : What's hard on them is that someone they love has cancer. We do have monthly family meetings at which the spouses, children, and parents of the patients come in and talk about their side of it. John, Debbie's husband, actually put it very beautifully. He said, "You know, at first I hated the cancer. I was angry at it. And then I realized that if I hated the cancer, I hated Debbie, because she had cancer, and part of what she was was that." Many of the members in the room were a little shaken because their own denial was punctured by the fact that one of the members had died. They came to feel that to really be close to the person who had cancer, they had to allow

themselves to feel all the discomfort that comes with knowing what

▽cancer is and what it can do. One husband left the meeting saying, "I've been putting off that discussion with my wife about what this means, and I'm going to go do it now." Dying is terrible, but dying alone is worse. And to allow the cancer to interfere with the caring you have for one another is really tragic and unnecessary.

MOYERS : How common is breast cancer in this country? SP I E G E I. : Breast cancer is distressingly common. One in nine women will get breast cancer at some point in their lives. One way to think of it is that a 747 full of

▽women get breast cancer every day in the United States. And a 747 full of women die of breast cancer every third day.

MOYERS: What's the difference between breast cancer and metastatic breast cancer?

SPIEGEL : Breast cancer is a very treatable illness, and the earlier it's caught, the more treatable it is. If the cancer has not spread to other parts of the body; the odds are quite good that it may never do so, and the women will live to die of something else. But once the cancer has spread to some other part of the body which is what we call metastatic breast cancer, then the problem shifts, and the question is not whether one will die of the cancer, but when.

MOYERS : How long do these women with metastatic breast cancer have to live?

SPIEGEL : After the cancer has returned, the average survival time is two years, although some people survive a long time, even with metastatic breast cancer.

MOYERS : So when you work with these women you know you re not going to save them.

SPIEGEL : Yes, that's clear. But what I find very rewarding is getting to know them and trying to help them live as richly as they can with the time they have, because the issue that we deal with in the groups and the issue in all of our lives is really quality, not quantity. It's how you live your life, and how fully you use your own resources, and do what you want to do in the world, and make and cherish relationships that are important. Some people do that in two months, and some people never do it in a lifetime. I find it a privilege to help these women live the lives they have as fully as possible.

MOYERS : If the findings of your study are replicated, what do you think it means for medicine?

SPIEGEL : It will be very exciting, because if they're replicated, what it means is that we have to change the definition of what health care is. We have to add to the surgical and medical interventions-which we're doing with increasing skill-a standard

component of treatment that involves helping the person who has the disease deal with it and feel supported through it. It means that health care is more than just physical intervention. It's support from a caring physician and health care team and some kind of group intervention to help people who are seriously ill learn how to cope with it as fully as possible. That would be a wonderful change in the direction of health care and a cost-effective addition to helping people live better and perhaps live longer.