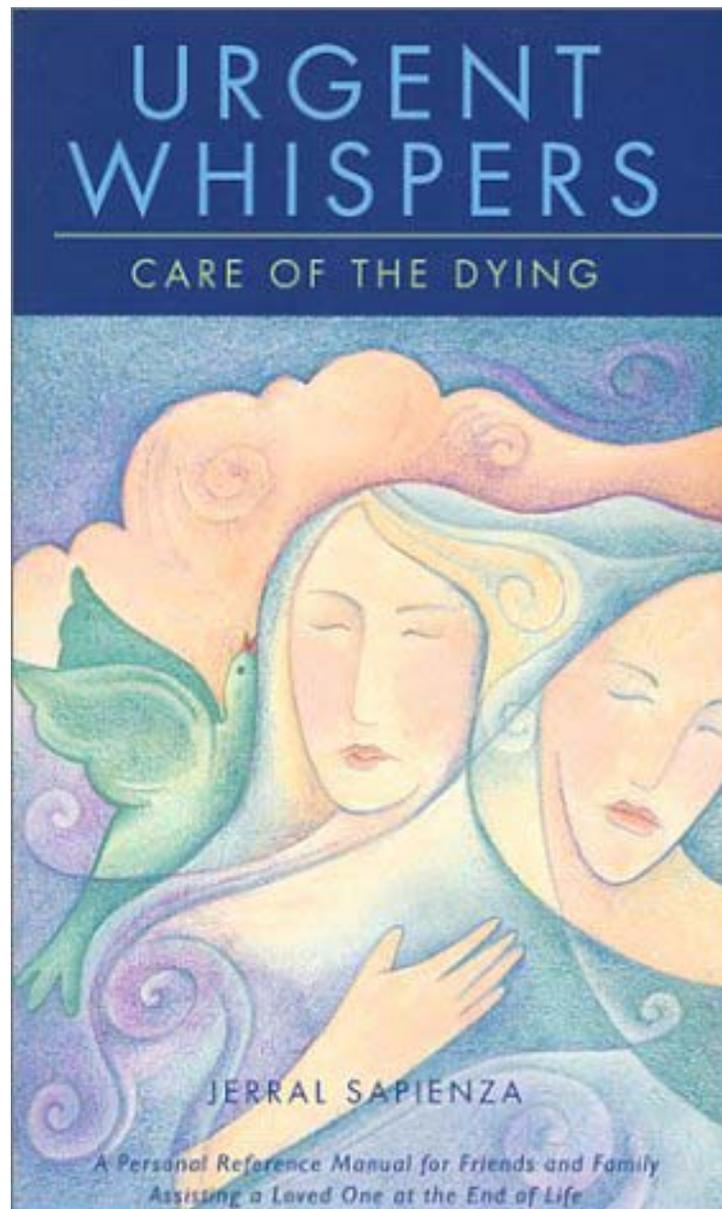


CAREGIVER TRAINING & DISCUSSION MANUAL

COURSE FACILITATOR'S GUIDEBOOK

for use with

URGENT WHISPERS: CARE OF THE DYING from LLX PRESS

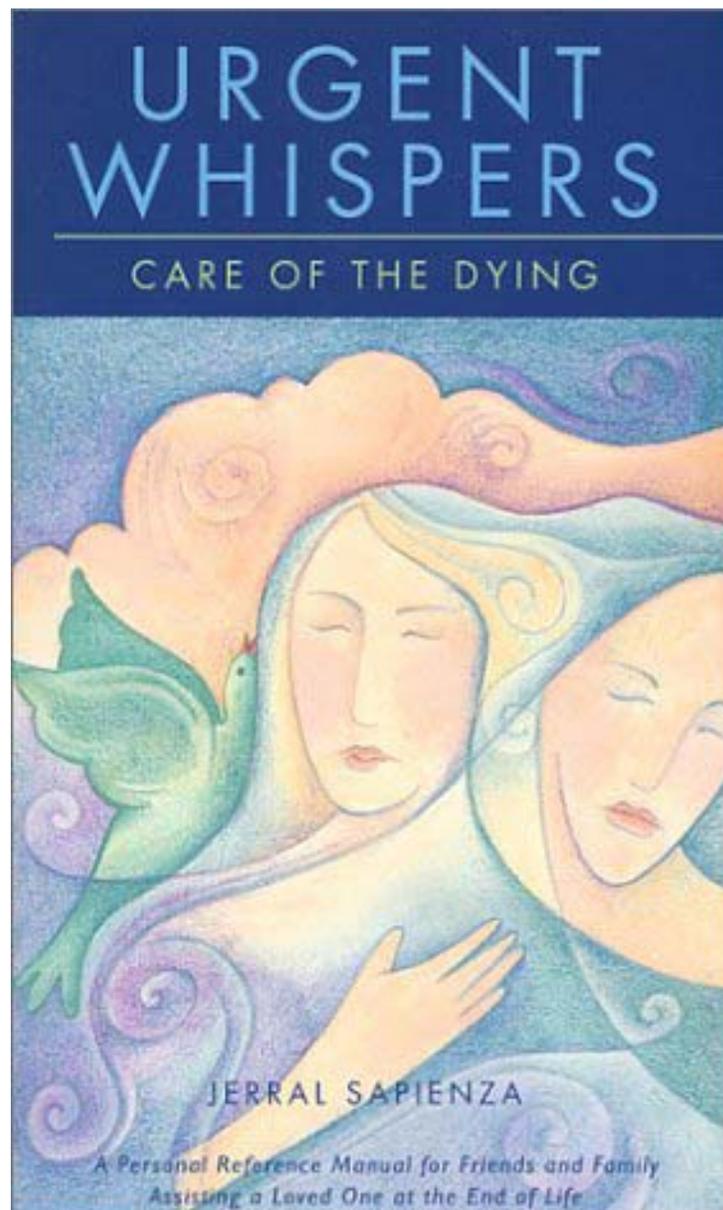


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URGENT WHISPERS: CARE OF THE DYING from LLX PRESS



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JERRAL SAPIENZA'S
**URGENT
WHISPERS**
CARE OF THE DYING

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R93

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CAREGIVER TRAINING & DISCUSSION MANUAL

COURSE FACILITATOR'S GUIDEBOOK

Additional copies of this booklet are available
from the LLX Press *Urgent Whispers* Training Web at:
<http://WWW.LLX.COM/UW/Train/>

Class One:
Urgent Whispers: Care of the Dying
Introduction of the Group, the Book, the Intention.

Adjust all times shown here accordingly to your chosen schedule. Shown here as offset from start time=00:00, through end time=02:00.

00:00 - 00:05 **Class Opening**

Text for Class: *Urgent Whispers: Care of the Dying* by Jerral Sapienza, LLX Press, \$14.95

Housekeeping Notes: It is a good idea to stress the necessity and respect of **starting classes “on time,” whatever time you as a group agree to.** Otherwise some folks can tend to straggle in late and interrupt the flow of comfortable or delicate discussion. No need to follow exact syllabus time spans but **try to create a group agreement of start and end time boundaries to honor.** Consistent class Opening and Closing procedures or rituals help contribute to a comfortable and trusted sharing environment. *Please Note: Allowing for the possible emotional nature of some topics, you may wish to have some boxed tissues available, and suggest to the group that accepting each other's laughter & tears is a normal, healthy, respectful part of such a class.*

Dedication Opening (Poem from page 5):

Perhaps read (this or another) dedication or poem aloud together as a kind of invocation to help remind of the group Intention:

*For those whose lives have gone before,
they blazed their trails whispering
to those still here behind this door
in urgent hopes we're listening...*

Declaring an intention of Sacred Space for the group to come together and share. Why are we here?

Facilitator Notes: Ideal group size is between 8-20. Larger group sizes tend to cut into group discussion time or feasibility. In order to amply share in discussions, it is best to keep a group less than 20, or have more than one group if necessary. Seating arranged in a circle is often most effective. This aids in the mood and attention of discussion and sharing. And if you are in a setting where it is safe and possible, it is a nice touch to be able to start a session with lighting of a candle placed in the center of the group. There is an archetypal instinct of “sharing around the fire circle,” a comfortable flickering flame in the center of the discussion offering a sweet calm repose. A dancing flame also serves a kind of metaphor for the precious light and breath of life and the reminder of its gift in our lives. **Several interesting discussion points:** We are here in a kind of “conspiracy,” speaking of life and death and love and priorities, not always easy subjects. The word *conspire* coming from the Latin roots, *con* (with) and *spirare* (to breathe): We are here to breathe together in a “conspiracy” quest to learn, grow and share in this experience. You can start each class if you wish, with the lighting of a candle and a conscious “breathing together,” (taking a couple deep breaths in unison, in a spirit of the intention of Sacred Space to link, relax, share.) The word “Spirit” by the way, also comes from the root *spirare*. Spirit=“The Big Breath” or “The Breath of God.” Sanskrit “*hu*” (the root of “human”) also=“Breath of God.” And finally, *whisper* of *Urgent Whispers* is from an imitative / onomatopoeic sound: *whisper* = a tiny spoken *breath*.

00:05 - 00:10 **Facilitator overview: Confidentiality, Communion, Compassion.**

Please remind folks that everything mentioned here in the group is to be treated as confidential, not shared outside this group without permission.. This is to be “safe space” for coming together (communion) and sharing openly with an ear to understanding (compassion) with one another. We're here to Learn, Grow, Share. Short group Q&A now re: Purpose.

00:10 - 00:40 **Group sharing:** Each person's introduction (jot notes if you wish) (*See Facilitator Notes, top of next page*)

Some intro materials: Your name? Tell us a hobby or of a “secret skill” you have but may not be known for?
What is your favorite travel destination? What was your favorite pet in all your life?
Do you know any / many other people in this calls here yet?
Any interest or experience in Hospice? Ever accompanied a friend or loved one on a death vigil?
How do you hope to Learn, Grow and Share in/with the class?

00:40 - 00:50 B R E A K

Class One cont'd

Each Class splits across two-page spread like this, with plenty of room in student guide for notes.

Group Introduction Time: Introduction questions are a series of fairly nonthreatening questions just to get to know a little bit about each person. Tell them to feel free to skip or improvise, and just let us get to know them a little bit better. At a minimum, do answer the “Your Name” and the “Do you know any/many people in the class?” and a couple others. For a more effective use of the individual introduction time, allow 3-5 mins “interview time” and have folks pair up, learn answers to each other’s questions, jot them down in the space provided in their booklet, then introduce each other instead of introducing themselves. Call time in 3-5 mins and get started around. This format of introductions helps to even out total discussion time so that everyone gets a chance to speak and have something said about them. And since they’re introducing each other, it is also less likely that any one person will tend to dominate. If you find you will be significantly over or under the allotted **30 mins total time for the entire group**, you may wish to offer suggestions for adding to or trimming the introduction material requested.

Every class has a BREAK time built into it, and that will generally give you an opportunity to break up the discussions a bit so that things don’t get too “heavy” for any length of time. You may also find, however, that the group does not want / need a break, and really would prefer to just stay right through the full two hours unimpeded. This is up to you and the group.

00:50 - 01:40 From **Table of Contents** of *Urgent Whispers: Care of the Dying*, review each of 52 “*whispers*” discussing briefly. What does it seem to mean?

Read aloud each *whisper* as a group or alternating readers, around the circle if comfortable with that. Elicit some basic discussion but no need at this time to get too in-depth; this is primarily to precondition discussion about the *whispers* in context later, and to familiarize class with the basic material as an overview. Discussion BEFORE reading the book is actually a useful exercise in alignment as we go along, and helps to see where we may need to focus more in-depth later on, as indicated by this discussion.

01:40 - 01:55 Q & A and discussion of anything presented thus far. Take this time to get to know the Group and Facilitator and chart Direction for the Class.

Though you have 15 minutes allocated for this exercise, it may seem for small classes to be entirely too much time, and for large classes, too little. In general, since this is the first class, this is perhaps a good time to review any specific subjects or materials folks had questions about earlier, or to present other local materials such as organizational expectations, continuing education certifications and requirements, etc. If you’re running way over, trim this time; if you’re running early, then you can ask questions for the group to share among one another like stories of Vigil Experience, Hospice Experiences, etc. Getting to know one another early on will help to later build a good rapport for engaging with one another to get more out of the class experience.

01:55 - 02:00 **Class Closing**

You may find that keeping a consistent Class Closing Ritual will be useful to help set the tone and boundaries for the class. One option is to close with a prayer or a poem each time. **The book contains a closing poem on page 141** which you could use; or you may wish to make a ritual of extinguishing the session candle each time as a symbolic close out; or you might make a more physical ritual by tearing down the circle, stacking the chairs, cleaning up, etc. Some groups have a kind of “social time” after class where the participants graze on munchies, mingle and talk a bit more in informal smaller groups. Use your own experience to help create the most workable boundary for a class closing ritual. But just as the Class Opening Ritual should be consistent, it is always a good idea to try and keep this Class Closing as consistent as possible, again, to help define boundaries and intention.

Class Two:
Urgent Whispers: Care of the Dying
Intro pages (17 - 32)
and *whispers* through page 43

00:00 - 00:05 **Class Opening**
Lighting the Candle - Breathing together - Settling in - Opening Dedication

00:05 - 00:50 Pages 17 - 32 Reading and discussion in class. .

This session's reading and discussion time can be done in a variety of ways:

- Read aloud the entire page 17 - 32 spread, alternating (optional) readers around the room.
- There are a number of themes here which can make for strong and enlightening discussions
- Certain of the themes or stories here may bring out some of the personal stories from the group
- Page 17 Quality of Life / Quality of Death issues
- Page 18 The legacy of societal changes and why we don't reach out
- Page 22 The "Teacher Times of Trauma"; What gifts have they held for you?
- Page 23 The book as Travel Planner and Guidebook
- Page 24-25 Jewel in the Darkness: the kinds of gifts we receive in spending time with a loved one
- Page 26-27 Asking for Help along the way
- Page 29 The Whispers format
- Page 30-31 Vigil Notes and Exercises: what is their usefulness in the process?

00:50 - 01:05 **B R E A K**

Class Two -cont'd-

01:05 - 01:45 Review each section / whisper, again reading aloud throughout.

As you discuss these, take the time to read them aloud. Pause and let silence pass for up to a couple minutes if necessary, even though any more than about 15-20 seconds of silence is almost impossible in an "active" group situation. Why do some of the discussion topics in *Urgent Whispers* evoke that silence?

32 - 33: **Vigil Record**

The Vigil Record is filled out by the person sitting the vigil, with the Loved One's name at the top, the Vigil Sitter / Reader's name next, then dates of when the vigil takes place, and where. This page serves as a beginning document for the vigil on which we now embark. Something like what we find in Family Bibles of old.

34 - 35: **Feeling Your Place**

Self-explanatory, this one and the next.

36 - 37: **Being Comfortable**

38 - 39: **The Breath Budget**

Concept of the Breath Budget is an important one for caregivers to understand. There is a very different kind of questioning and vocal assessment we use with a patient who can't respond very much or very easily. You may want to talk about different good breath-budget questions, and do some role-playing with it.

40 - 41: **Priorities**

Priorities is often a lively discussion. In order to get some thought going, you may wish to pose a question something like: *If you knew you only had two weeks / two years / two days to live, what different choices might you make?"*

42 - 43: **The Gatekeeper**

Gatekeeper is another important idea. You may wish to guide the discussion to *how* a gatekeeper happens... it's not so much an appointment as it is an emergence of the role. Why might some people make particularly better/worse gatekeepers than others? (it's usually some issue re: control issues and open-mindedness.)

The Robert Frost poem, *Mending Wall* is an interesting thing to mention... (lines 32-36 of the 46 line poem)

...
*Before I built a wall I'd ask to know
 What I was walling in or walling out,
 And to whom I was like to give offence.
 Something there is that doesn't love a wall,*
 ...

01:45 - 01:55 Q & A - Further Discussion

01:55 - 02:00 **Class Closing**

Class Three:
Pages 44 - 51
Urgent Whispers: Care of the Dying
Concepts of Caring
Truth / Dignity / Grief / Compassion

00:00 - 00:05 **Class Opening**
Lighting the Candle - Breathing together - Settling in - Opening Dedication

This session is where some of the complicated and heavy issues and discussions begin. It appears that we haven't so much to discuss today, and yet these issues aren't simple. But if the group does indeed move quickly through this material, you may want to move into next session's since it is a very long list of topics for one class, noting where you leave off. But don't get too far too fast... let comfortable (or uncomfortable!) silence pass if folks seem to think there's nothing more to say on some of today's issues.

Often it's just a matter of them not being 100% comfortable yet talking about some of these things. Your own finer communication and leadership skills are very useful at this point, for sensitively evoking some responses without being too pointed. Try not to just ask questions... lead out the discussion with open ended discussion cues. If things seem too quiet or too slow in starting, then try speaking about some of your own experiences on some of these subjects.

00:05 - 00:15 Recap and Discussion of Old Issues, Questions from Class Two, etc.

Breath Budget, Priorities & Gatekeeper issues may be good class starters for this session if no one has other discussion topics. They're good to review as we lead into tonight's discussion topics.

00:15 - 00:45
44 - 45: **Telling the Truth**
You may wish to guide one focus of the discussion to couplet poem at the bottom of page 45.

46 - 47: **Dignity in Care**
Big issue here... Everyone deserves to be treated as a whole and complete being. How can we best do that?

00:45 - 00:55 B R E A K

Class Three -cont'd-

00:55 - 01:45

48 - 49: Grieve not yet...

This may tend to be a hot-button topic for some people; though they may understand the nature of the point, they may still want to strongly disagree. You may have folks pointedly defending their "right" to grieve, and wondering why not.

Help point out that we're delaying grief while in the room but that isn't really denial, but respect. Folks are still encouraged to begin to deal with their grief, but just not in the room... in most cases it's better to wait til they get home or in another space, unless as a team the dying party and the caregiver are dedicated to a process of working out some of these things together (usually earlier on in the process.)

You may want to talk about the classic stages of grief in Kübler-Ross: **Denial, Anger, Bargaining, Depression and Acceptance**, noting where we are apt to be in the "stages" when we're at the bedside. Unless we're truly all the way to "Acceptance," then there will be opportunity for rocky emotional times, and it's those rocky times we're trying to mostly steer away from the bedside if we can.

50 - 51: Pity & Compassion

Another of the potentially hot-button topics. Pay special attention to the 2nd and 3rd paragraphs on page 51, "Compassion is..." and "Pity, on the other hand,..."

01:45 - 01:55 Q & A - Further Discussion

.For further discussion, you may want to lead off with the when did I last *feel pity* and *feel compassion* from p.50

01:55 - 02:00 **Class Closing**

Class Four:
Urgent Whispers: Care of the Dying
Pages 52 - 77
Environment - Emotions - Beliefs

00:00 - 00:05

Class Opening

Lighting the Candle - Breathing together - Settling in - Opening Dedication

00:05 - 00:50

We've got a lot to cover in this session though they're not as "heavy" as last session's topically. This class forward, there will be no recap at the beginning of each class. If it turns out that folks seem to have many old topics they need to discuss, you may need to shorten some discussions. (Or you may also wish to see if the class truly requires taking breaks half-way through a discussion, or would perhaps prefer to carry on with discussion while those who need to take a break do so quietly.) Throughout today's topics, some of the typically stronger focal points for discussions are noted below.

NOTE: #1 Most important *must-discuss* topic today is pages 74 - 77 on Beliefs.

52 - 53: Taking

Focus on 2nd paragraph p53 "This is not the time..." / Top p52: Resentments, loss, abandonment.

54 - 55: Denial

Note concept of "so soon" p55 3rd paragraph; couplet at bottom p55

56 - 57: Getting By

Note top 57 whisper: "Are you taken care of..." and par 2 "Think what it must be like..." You may wish to point out that this is along the idea of "letting go" which we'll see more of later...

58 - 59: Food

Note the bottom of pg 59 "An occasional meal of your own..." as a special kindness

60 - 61: The Senses

Many people seem surprised about the way senses seem to sharpen / fade at this time. Note last par of pg 61 "It is most disconcerting..." for discussion point about which folks may have stories.

62 - 63: Flowers & Perfumes

Caregivers often say "I never thought of that before." Focus end p63: "Beauty never overpowers."

00:50 - 01:00

B R E A K

Class Four -cont'd-

01:00 - 00:45

64 - 65: We're all Equals

This is an interesting reflection for caregivers which, again, they may not have yet considered.

66 - 67: Sitting Vigil

Discussion topic could be about sitting vigil alone or with others, pro's & con's of each.

68 - 69: Sadness

This one is sometimes another hot-button like the grief one from last class

70 - 71: Respect

This one is another of the "respect" and "acknowledgment" ones. Any folks have stories?

72 - 73: Relaxation

Discussion of folks' effective music experience, environment etc. may be interesting to all.

74 - 77: Beliefs

#1 Most important section of the book! Make sure there is adequate time to discuss 74-77.

01:45 - 01:55

Q & A - Further Discussion

01:55 - 02:00

Class Closing

Class Five:
Urgent Whispers: Care of the Dying
Pages 78 - 99
Tuning in / Old and New Bonds / Onward

00:00 - 00:05 **Class Opening**
Lighting the Candle - Breathing together - Settling in - Opening Dedication

00:05 - 00:50

78 - 79: **Friendship**

80 - 81: **Pleasantries**

Echoes here of page 37. Special attention can also be paid to getting children involved. See last paragraph p.81 and question at bottom of p.80.

82 - 83: **Grudges**

This one usually encourages responses and discussion... sometimes a hot-button or stories issue.

84 - 85: **Distractions**

Another hot-button item for some folks' defenses, especially being challenged on the "doing." Specifically try to discuss the exercise at the bottom of p.84, since the point is well made there.

86 - 87: **Tuning-In**

Point out the basic points of pars 2 & 3 on p.87 if you have time for more discussion (letting go and control issues). Also: good exercise on p.86, which you may also wish to try out in class as example of how it 'feels.'

88 - 89: **Remembering**

Value of Committing to Remember as an exercise in grief for later, as well as commemoration. Talk about some of the possibilities for the exercise on p.88.

00:50 - 01:00

B R E A K

Class Five: -cont'd-

01:00 - 00:45

90 - 91: Honoring

These are about issues of respect, diversity, variety and non-judgment. Challenges at any time, but especially when nerves and emotions run more raw.

92 - 93: Synchronicities

A very important way to begin to tune into some of the "Life Oracles" which help us see the world more clearly by tuning into some of the less obvious clues around us. The upcoming book from LLX Press, **Urgent Whispers III: Tending Life's Oracles** is another book folks may want to know about which ties into the concept of synchronicities.

94 - 95: Dies with me

This is a tough one for some folks. Focus discussion on Comfort / Reflection / Connection.

96 - 97: Writing

Triplet at bottom of P.97 is particularly useful here. Discussion of usefulness of journals.

98 - 99: What time is it?

Discussions on this one range from ecstatic enthusiasm from some people to fear and trepidation from others. Consider the variations in 2nd paragraph. Re-link that point on the Breath Budget from earlier discussions.

01:45 - 01:55

Q & A - Further Discussion

01:55 - 02:00

Class Closing

Class Six:
Urgent Whispers: Care of the Dying
Pages 100 - 125
Touching the End / Hereafters / Thank You

00:00 - 00:05 **Class Opening**
Lighting the Candle - Breathing together - Settling in - Opening Dedication

00:05 - 00:50

100 - 101: Touch

Consider Touch and Proximity as mentioned on p.100.

102 - 103: Guides

This topic can sometimes be controversial to some people because they just don't understand. Tie it in with Beliefs 74-77 in discussing how we can't limit other people's experiences by our own lack of understanding, and yet if our minds are open, we stand a chance to Grow. Allow and welcome time for stories.

104 - 105: Last Requests

106 - 107: Cathedral

See last paragraph on p.107 for the cathedral analogy. First par p.107 is the "why" of it.

108 - 109: Schedule

Reminder here is Patience, Faith and Trusting the Big Picture. The desert analogy sometimes causes people to cry... they get it. Compare also with "so soon" of Day 4, p.55.

110 - 111: Celebrate

This one also is an emotional one, but on the other end... it has a kind of comforting tears of joy effect on people.

00:50 - 01:00

B R E A K

Class Six: -cont'd-

01:00 - 01:45

112 - 113: Teacher

Last two paragraphs on p.113 are most important here, plus the couplet. This is another one which will generally evoke good discussion.

114 - 115: Humanity

Analogy of the rose is useful in understanding the importance of the "Present" and the "fulcrum of eternity" in paragraph 4. P.114 "Wake-Up Call" is good discussion exercise.

116 - 117: GoodBye

"Letting go" again, this time the physicals. Note end par 2 asks that all-important: "Have you?"

118 - 119: Release

"Permission to die" concept at end of par 2 is the place to focus discussion in this one. There may be some good stories which want to come out on these topics.

120 - 121: Eternity

This is an opportunity to discuss "Beliefs" again, as well as religion.

122 - 123: Thank You

Another one which often elicits tears of joy. This is a good focal point for support strokes.

124 - 125: Understanding

Ending triplet here says it all. Discussion can be of how many folks volunteering at hospice came to it from the death of a loved one, or some other similar experience. Good place for more stories, and this is a good place to end on a warm-fuzzy type feeling for this session.

01:45 - 01:55

Q & A - Further Discussion

01:55 - 02:00

Class Closing

Class Seven:
Urgent Whispers: Care of the Dying
Pages 126 - 151 (end)
Final Process / Lessons / The Way Back

00:00 - 00:05

Class Opening

Lighting the Candle - Breathing together - Settling in - Opening Dedication

00:05 - 00:50

126 - 127: **Symptoms**

This is sometimes a difficult thing for people to look at or discuss, especially if they're currently still sitting with a loved one who has not yet died. But it is important that they are aware of it.

128 - 129: **Knowingness**

This proverb can be of some strong solace to folks who have experienced this sort of awareness in their friend or loved one. But then, also, the "All grows still..." can be a little disconcerting with the final paragraph's a double-edged vision of it all.

130 - 131: **Calm**

You may want to discuss some of the Buddhist / Tibetan / Hindu or other Eastern views of those final few moments of life being the most important. There will be stories looking to come out, almost certainly, around some of these "final moments" experiences within the group.

132 - 133: **Cocoon**

The bittersweet moment the whole process is built upon... certainly there will be emotions and stories here. Notice the mentioning of "the Way Back" in the next to last couplet. There is another "Way Back," too... *Urgent Whispers II: The Way Back*, LLX Press's next book in this series, having to do with "the Way Back to Life after Caregiving", a collection of personal grief coping rituals.

00:50 - 01:00

B R E A K

Class Seven -cont'd-

01:00 - 10:30

134 - 135: Respite

There is on p.134 an exercise/discussion topic about sample "closing rituals" which may be useful for a good class discussion now. You may also wish to point out the differences between 100 years ago and today, as to how Americans deal with death, the dying, and the dead.

One example: homes in early America, as in many other western cultures, had "parlors" which, though they had other social uses, were specifically designed to be able to accommodate a coffin and a few sitters or mourners so that the family folks could whenever necessary be able to prepare and "sit with the body" after death.

Modern American houses (especially post-WW II) completely dispensed with the concept of "parlor" at all, and in fact, invented a completely new concept, with a defiant new name: "living room" as if to say, "*And this ain't no parlor; no coffins welcome!*"

This custom has completely revolutionized that age-old "closing ritual" of sitting with the body and saying the good-byes, and instead, we moved that entire experience into a whole new outside-the-home industry, what we now refer to as "funeral parlors." The modern American home (and culture, for that matter) has for the most part no accommodation whatsoever to consider the possibility of receiving a coffin and mourners at the home. These are very different mores and values than our ancestors a mere 100 years ago!

136 - 137: Lessons

This is another invitation to discussion which we can expect. There are generally some very strong (positive) emotions about the Lessons of Love one learns in death.

138 - 139: Afterword

It's probably a good idea to speak a bit about where we go from here... This "after the fact" time is a particularly vulnerable place for many folks to be, and a time when depression, confusion and other manifestations of grief hit. Certainly that is only the beginning in many ways, even though it has been the end of other processes, times, trouble.

Another interesting discussion from the end-thoughts is the relative value of sharing the vigil records / exercises filled in here with others. Some folks find that the exercises are a bit too private to be sharing even with family members, while others share it all completely openly, even what may seem to some of us as the more intimate exercises such as those on p.50 and p.52.

01:30 - 01:55

Q & A - Further Discussion on any of the topics of the class.

01:55 - 02:00

Class Closing

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Course Name URGENT WHISPERS: Care of the Dying Training & Discussion Date: _____ to _____

Location: _____ Facilitator: _____

N/A	No!	Perhaps	Somewhat	Mostly	Yes	Absolutely!		
0	1	2	3	4	5	6	7 8 9 10	
0	1	2	3	4	5	6	7 8 9 10	The course met or exceeded my expectations.
0	1	2	3	4	5	6	7 8 9 10	My comfort level as a caregiver has improved.
0	1	2	3	4	5	6	7 8 9 10	The Facilitator helped create a comfortable learning environment.
0	1	2	3	4	5	6	7 8 9 10	Sharing the class with these students has been a pleasant experience.
0	1	2	3	4	5	6	7 8 9 10	I find <i>Urgent Whispers: Care of the Dying</i> a useful book.
0	1	2	3	4	5	6	7 8 9 10	The class discussions were interesting and thought provoking.
0	1	2	3	4	5	6	7 8 9 10	I have come away learning more about Life as well as Death.
0	1	2	3	4	5	6	7 8 9 10	Course pacing allowed adequate time for material to be covered.
0	1	2	3	4	5	6	7 8 9 10	Class meetings were held in an appropriate and pleasant space.
0	1	2	3	4	5	6	7 8 9 10	The Overall Course was interesting, memorable and useful.
0	1	2	3	4	5	6	7 8 9 10	The Training Manual was well presented and useful.
0	1	2	3	4	5	6	7 8 9 10	Overall, the Facilitator is an effective facilitator / instructor.
0	1	2	3	4	5	6	7 8 9 10	I will recommend this course to others.

How could the overall Course be improved?

Other comments about the Course:

How could the Facilitator or Instructor's methods improve?

Other comments about Facilitator / Instructor:

Other general or specific comments:

Notes

