CLiP

15 minute Workshop


## Psychological needs

# 8: Collusion and denial

**Advanced level**

Produced by
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**Aim of this worksheet**
To develop some insight into collusion and denial by a patient, partner or relative.

**How to use this worksheet**

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know.
- Take this learning into your workplace using the activity on the back page.

**Case study**

**Peter is a 46 year old man, married with two children who was diagnosed with motor neurone disease. He wanted to know the diagnosis and was told. He has been deteriorating rapidly this past week. Now back at home, you have been asked to visit by his wife Dora and daughter Angela.**

**When you arrive they explain that Peter doesn't know you have been called. You decide to see Peter for yourself, but at the bottom of the stairs, Dora grasps your arm & tells you Peter doesn't know he is dying & she & Angela have decided he should not be told. Dora thinks it best if you go outside & ring the doorbell, to make it look now as if you have just called in routinely to see Peter.**

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## INFORMATION PAGE: Collusion and denial

### Getting started

Like much else in health care, it is important to keep an open mind. Don't assume that collusion and denial are bad or good- the issue is whether they are helpful or unhelpful to those involved.

### Definitions

*Collusion*: this is something you do to another person and implies the withholding of information amongst individuals involved, eg. a wife chooses not to tell her husband that he is seriously ill, or patients choose not to tell their family about their illness. It is 'denial-by proxy'.

*Denial:* this is something you do to yourself and involves avoiding information and the resulting thoughts and feelings that may be too painful to face, eg. a patient refuses to accept the full reality of their illness. It is not the same as a gap in knowledge since you have to deny something! On the contrary, it is due to the individual struggling to cope with the knowledge they do have- it is an overload of reality.

### Your reactions

When you first meet someone who is colluding in keeping information from their partner or relative, your reaction may be any of these:

- Surprise at the person's comments.
- Annoyance that someone is intervening between you and your patient.
- Confusion as to what you should say now.
- A desire to join with the person and protect the patient.
- A desire to protect oneself from the emotional outburst or response to bad news.
- A determination that the patient should have the opportunity to decide for themselves.
- A wish to enable the patient and person to work this out together.

### MCQ answers

1. **F** Agreeing to their deception is collusion. It is not a promise you can keep without first talking to Peter.
2. **F** This is going too far the other way- they may be right, after all!
3. **F** Now you are getting cross about the collusion and colluding at the same time!
4. **T** You need to start a dialogue with Dora and Angela to explore their feelings.
5. **T** Reality about death, dying and disability can be difficult to face. Not talking about reality can be a good coping mechanism, as long as it is working for the individual and is not at the expense of the patient.

### The pros and cons of collusion and denial

| **The good things:** | **The down side:** |
|---|---|
| *Collusion* | *Collusion* |
| Usually an act of love | Occasionally reflects control over the patient |
| Provides a sense of protecting the patient | May isolate and patronise the patient |
| Both person and patient may agree to collude! | May strain relationships because of 'secrets' |
| Superficially easier for carers | May increase anxiety or depress mood |
| Offers mutual protection | Can create a 'conspiracy of silence' and distrust |
| *Denial* | *Denial* |
| Allows information to be managed in stages | Can prompt carers to push information |
| Does not prevent consent for treatment | Can prompt carers to insist on sharing information |
| Can be an effective coping mechanism | Can delay the sorting out of important business |
| | Can interfere with ability to make decisions about future care |

### The next step

*What can you say that might help Dora & Angela?* It can help to reflect the loving care that is being shown to Peter eg. "I can see that he has been hurt – you have all been hurt - by this devastating diagnosis and you do not want him to be hurt any more." Explain that you would be guided by Peter in the consultation, but if he asks outright then you would take it as an indication that he is ready to start discussing the diagnosis.

*Telling or not telling:* it is a professional's duty to find out how much the patient wants to know, not to decide whether the patient should know. See the CLiP worksheet on *Breaking Difficult News.*

*Should you 'fudge it'?* You could delay speaking to the patient on this occasion but do speak to the relatives. If you allow what you have said to sink in, it may break the collusion and allow more open communication next time.

### Summary points

Collusion is usually driven by love rather than control.

Collusion is usually estranging & isolating for all involved (professionals too!).

The purpose of tackling collusion is to enable closeness & honesty between those involved.

The key to moving forward with partners and relatives is to fully acknowledge that they are behaving in the most loving way they know, but then to outline the down side. It can help to point out that although collusion may seem the most loving thing to do now, how will the "missed opportunities" be viewed looking back in bereavement?

There are some situations when it is not helpful to challenge collusion eg if the patient is too ill to engage in the discussions needed or if the prognosis is too short to allow time for the discussions.


**Think about**

- **How you would feel?**
- **How you would react?**

Dora says you know nothing about her husband & she & Angela have talked long about what they are proposing & that to do otherwise would "destroy that dignified man up there".


- **What do you think of their plan?**

| | | | |
|---|---|---|---|
| 1. | Accept their plan & step outside to ring the door bell | True | False |
| 2. | Tell them you're leaving as you feel you are here under false pretences | True | False |
| 3. | Argue that you feel this arrangement is against your ethical principles but agree not to mention his deterioration | True | False |
| 4. | Sit down with Dora & Angela to enquire why they feel this way | True | False |
| 5. | Accept that not talking about death can be an acceptable way of coping | True | False |


**What are the pros & cons of their approach?**

| Good Things about collusion and denial | The Down side of collusion and denial |
|---|---|
| Collusion | Collusion |
| Denial | Denial |

You arrive at an understanding that you will not initiate discussion about his deterioration. Peter has been lightly dozing, but sits up and asks how much time he has left.


- What agreement would have to be agreed downstairs to enable a truthful reply?

- Is it your duty to tell the patient?

- What are the consequences if you "fudge" it today? Do you have to sort it all out today?

## FURTHER ACTIVITY: Collusion and denial

Reflect on a time when you colluded with someone.

- What were your reasons for colluding?
- With hindsight, was it the best way?

## FURTHER READING: Collusion and denial

### Journal articles


Benkel I. Wijk H. Molander U. Using coping strategies is not denial: helping loved ones adjust to living with a patient with a palliative diagnosis. *Journal of Palliative Medicine.* 2010; **13**(9): 1119-23.

Bruera E. *et al* A randomized, controlled trial of physician postures when breaking bad news to cancer patients. *Palliative Medicine*. **21**(6): 501-5. 2007

Cherlin E. *Et al* Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *Journal of Palliative Medicine.* **8**(6): 1176-85, 2005

Fallowfield LJ. Jenkins VA. Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Medicine.* 2002; **16**(4): 297-303.

Friedrichsen M. Milberg A. Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians' perspective. *Journal of Palliative Medicine.* 2006, **9**(3): 673-82.

Friedrichsen MJ. Strang PM. Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care--patient's view of the doctor giving the information. *Supportive Care in Cancer.* 2000; **8**(6): 472-8.

Jenkins V. Fallowfield L. Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer.* 2001; **84**(1): 48-51.

Kirk P. *et al* What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ.* **328**(7452): 1343, 2004

Lamont EB. Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine.* 2001; **134**(12):1096-105.

Paul CL. *et al.* Are we there yet? The state of the evidence base for guidelines on breaking bad news to cancer patients. *European Journal of Cancer.* 2009; **45**(17): 2960-6.

Shahidi J. Not telling the truth: circumstances leading to concealment of diagnosis and prognosis from cancer patients.

*European Journal of Cancer Care.* 2010; **19**(5): 589-93.

Steinhauser KE. Alexander SC. Byock IR. George LK. Olsen MK. Tulsky JA. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *Journal of Palliative Medicine*. 2008, **11**(9): 1234-40.

Stephenson PS. Understanding denial. *Oncology Nursing Forum.* 2004; **31**(5): 985-8.

Tuffrey-Wijne I. *Et al* People with intellectual disabilities and their need for cancer information. *European Journal of Oncology Nursing.* **10**(2): 106-16, 2006

Tuffrey-Wijne I, Bernal J, Hollins S. Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: findings from an ethnographic study. *European Journal of Oncology Nursing*. 2010; **14**(3): 224-30.

Vachon M. The emotional problems of the patient in palliative medicine. In, Hanks G, Cherney NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. *The Oxford Textbook of Palliative Medicine, 4th ed.* Oxford University Press, 2009, pp 1410-36.

Warnock C, Tod A, Foster J, Soreny C. Breaking bad news in inpatient clinical settings: role of the nurse. *Journal of Advanced Nursing.* 2010; **66**(7): 1543-55.


### Resource books


*Effective Interaction with Patients, 2nd ed* Faulkner A. New York : Churchill Livingstone, 1998.

*e-lfh: e-Learning for Healthcare* contains a range of online self-learning programmes, including several relating to end-of-life care (e-ecla). Registration is required but is free.

*Introducing Palliative Care* 5th ed. Twycross R., Wilcock A. www.palliativedrugs.com 2016

*Talking to Cancer Patients and their relatives*. Faulkner, A. Oxford: Oxford University Press, 1994.

*A Guide to Symptom Relief in Palliative Care, 6th ed.* Regnard C, Hockley J. Oxford: Radcliffe Medical Press, 2010

*Oxford Textbook of Palliative Medicine* 4th ed. Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. eds. Oxford : Oxford University Press, 2010.