

Positive experiences of patients and their partners

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Your positive experiences

- What positive experiences have you encountered among:
 - Your patients?
 - Their communication partners?

Joshua
Reynolds
1723-1792



Joshua Reynolds (1723-1792)

“Reynolds did not let his deafness worry him. It assisted his gift for reading character.”

Hudson, 1958

David Hockney
1937-

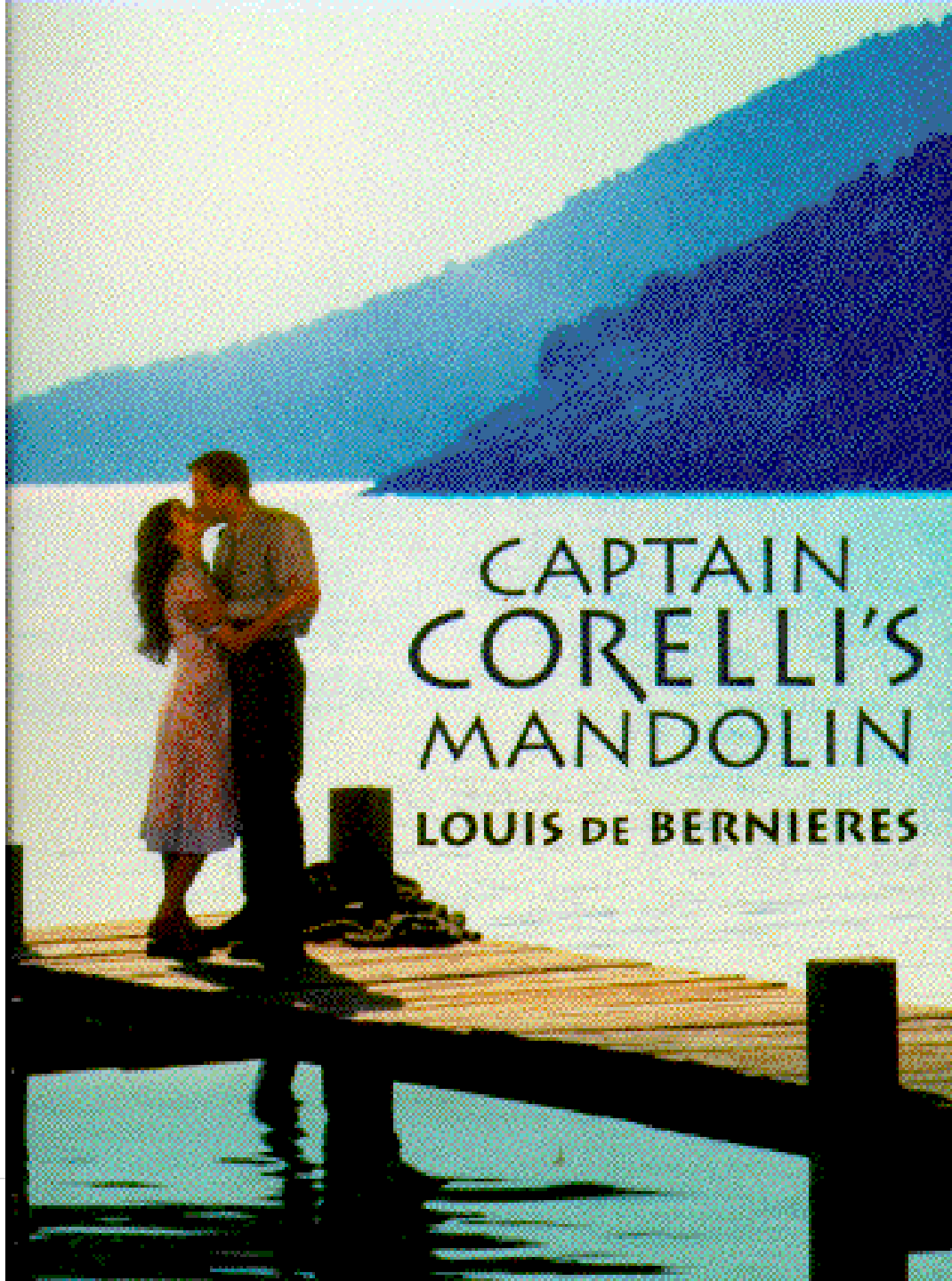


David Hockney (1937-)

“I think it makes me see clearer.”

(Because sound aids spatial localisation, he believes poor hearing must heighten his vision)

Garfield, 1997



CAPTAIN
CORELLI'S
MANDOLIN
LOUIS DE BERNIERES

Louis de Bernières - “Captain Corelli’s Mandolin”

“You know that thing in my ear?

....can you put it back?

Its my wife, you see.

Well, when I was deaf in that ear I couldn’t hear her and I could sort of take it.

The nagging....before it was sort of like the murmuring of the sea. I liked it. It helped me to doze off. But now it’s so loud.....it’s driving me crazy.”

Positive factors from other disabilities

- Events
- Activities
- Changes in Existential values
- Increased self-knowledge
- Relationship changes
- Life satisfaction
- Coping behaviours
- Adjustment

Post-traumatic growth inventory (Tedeschi & Calhoun, 1996)

- **Appreciation of life**
 - More appreciation of being alive
- **Relating to others**
 - Relates better to others than before
- **Personal strength**
 - Grown stronger as a person
- **New possibilities**
 - Possibilities they had not seen before
- **Spiritual growth**
 - Become more spiritual

Patient studies

Stewart Kerr PhD study (1992)* **Questionnaire study on Psychosocial effects of acquired hearing impairment**

Kerr and Stephens (1997, 2000) **Open-ended questionnaire**

Stephens and Kerr (2003) **Development of a quantitative measure**

*Stewart Kerr and Cowie, 1997.

Stewart Kerr (1992) Factor analysis

- Stronger religious feelings
- Understanding human nature
- Someone accompanies you
- People repeat themselves
- Enjoyable conversation
- People don't know I'm deaf
- Included in activities
- Allowances made
- People behave better

Kerr and Stephens (1997)
Open-ended questionnaire

Please make a list of any Positive Experiences which you have had as a result of your hearing loss. Write down as many as you can think of.

Kerr and Stephens (1997)

Most common themes reported

- Reduced disturbance from unwanted noise
- Successful communication strategies
- Affinity to people with hearing impairment and other disabilities
- Perceived self development
- Using hearing impairment to self advantage

Kerr and Stephens (2000)

Main themes

- Reduced disturbance from noise
- Communication strategies
- Affinity to people with hearing impairment or other disabilities
- Perceived self-development
- Technical aids
- Using hearing impairment to self-advantage

Stephens & Kerr (2003) – Quantitative measures

Proportion of positive responses

Qualitative studies 21.6% and 40.1%

Quantitative study >90% to certain questions

Explored

- The **nature** of positive experiences
- The **impact** of positive experiences
- The **function** of positive experiences

Factor analysis

(relative contribution of factors that account for 60.5% of variance)



Can communication partners have positive experiences from their partners' hearing problems?

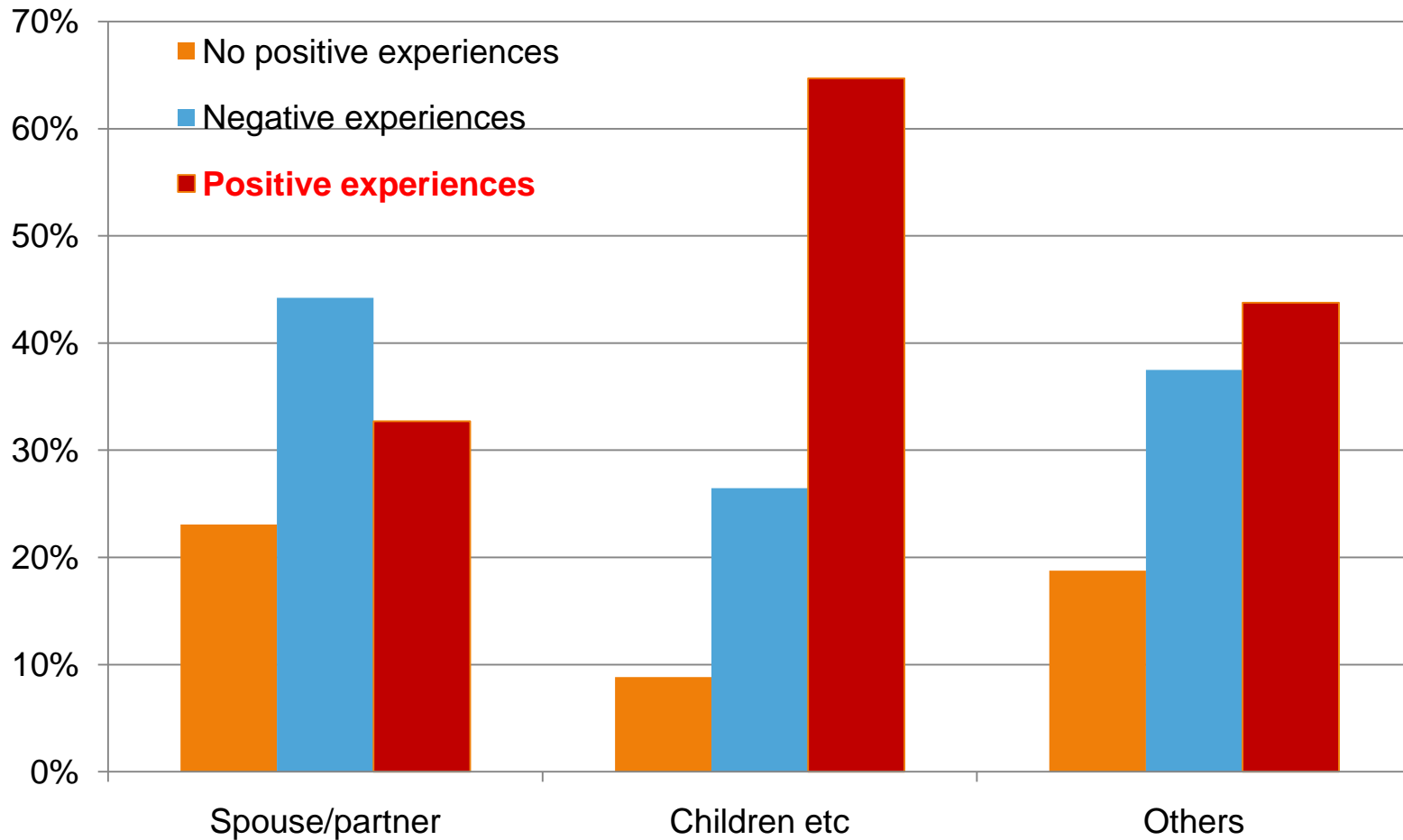
“Please make a list of any positive experiences which YOU have as a result of this person’s hearing loss. Write down as many as you can think of.”

Communication partners of 102 consecutive patients attending the Welsh Hearing Institute

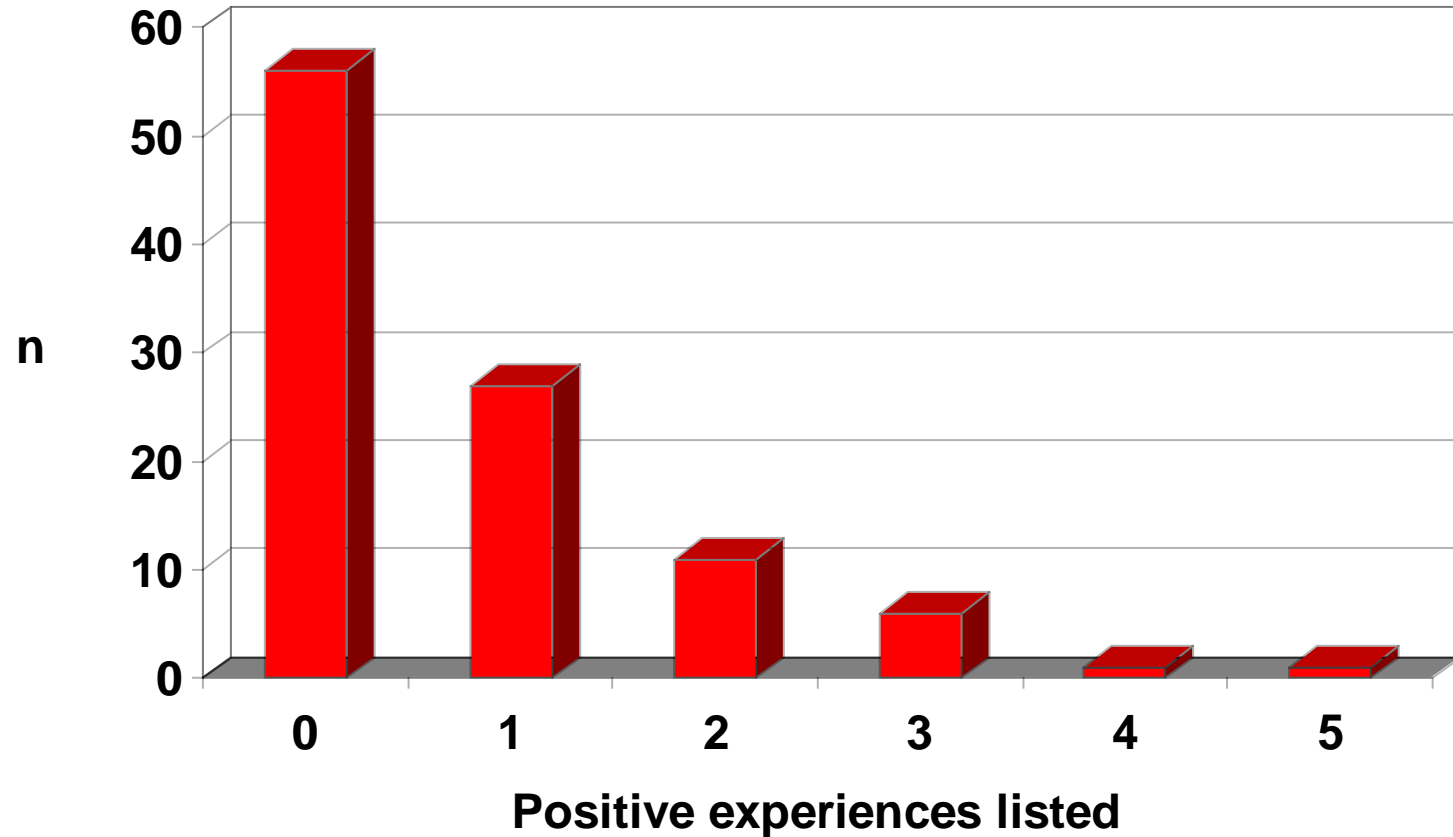
45% listed one or more positive experiences

Stephens, Kerr and Jones (2004) *Audiological Medicine* 2: 134-138

Types of response by relationship



Numbers of positive experiences listed by respondents



Most common positive experiences listed

- Development of patience and tolerance
- Understanding and awareness of hearing problems
- Improved communication skills
- Able to do things without the hearing impaired person hearing

Other positive experiences listed

- Increased awareness of the importance of their own hearing
- Appreciation of help received
- Increased emotional ties
- Humour
- Help for the future
- Miscellaneous

Communication Partner: Please make a list of any Positive Experiences which YOU have because of your spouse/friend's hearing loss

- *I realised that we couldn't make small talk and initially I was somewhat resentful. However, I began to realise I could relax a bit more than usual. I didn't need to be thinking about something to say next.*
- *There is much greater quality of events in my life – what we do is usually very nice and pretty satisfying.*

- *I listen to more beautiful music or different music, not so much junk.*
- *I am also much more aware of my own hearing and take care of it by avoiding unnecessarily noisy events and situations.*

Patient: Please make a list of any Positive Experiences which YOU have because of your hearing loss

Communication Partner: Please.....Positive Experiences which YOU have because of your spouse/friend's hearing loss

Patient

- *Generally listen more carefully*
- *Appreciate difficulties faced by hearing impaired people, especially the elderly*
- *Realise how much we rely on hearing and how much it enriches life*
- *More aware of body language*

Communication partner

- *Being careful to speak clearly and not assume everything said is heard and understood*
- *Realise that a secondary noise will cause problems*
- *Do not speak from behind. Establish eye contact first*



Patient: Please make a list of any Positive Experiences which YOU have because of your hearing loss

Communication Partner: Please.....Positive Experiences which your spouse/friend has because of their hearing loss

Patient

Communication partner

- *Generally listen more carefully* ←-----→ • *Trying to be in a position to hear and understand easier*
- *Appreciate difficulties faced by hearing impaired people, especially the elderly*
- *Realise how much we rely on hearing and how much it enriches life*
- *More aware of body language*

Patient: Please make a list of any Positive Experiences which your spouse/friend has because of YOUR hearing loss

Communication Partner: Please.....Positive Experiences which YOU have because of your spouse/friend's hearing loss

Patient

- *Provides an opportunity to exercise patience and accommodate other's disabilities*



Communication partner

- *Being careful to speak clearly and not assume everything said is heard and understood*
- *Realise that a secondary noise will cause problems*
- *Do not speak from behind*
- *Establish eye contact first*

Communication partners of cochlear implant users

“Please make a list of the benefits that YOU have noticed since your relative/friend has had a cochlear implant. Write down as many as you can think of.”

31 respondents (22 spouses; 5 children; 3 parents; 1 friend)

Kennedy, Stephens & Fitzmaurice (2008) *Otology & Neurotology* 29: 607- 614.

Functional benefits reported

- **Mental**
 - Increased happiness
 - Improved Quality of life
 - Less pressure on communication partner
- **Hearing**
 - Partners now responded when called

Improved activities for communication partners

- Ease of, and ability to have a, conversation
- Reversal of 'negative' behaviours (eg no longer need to repeat, write things down, shout etc)
- Able to converse without speech-reading cues
- No longer have to intervene on behalf of CI user

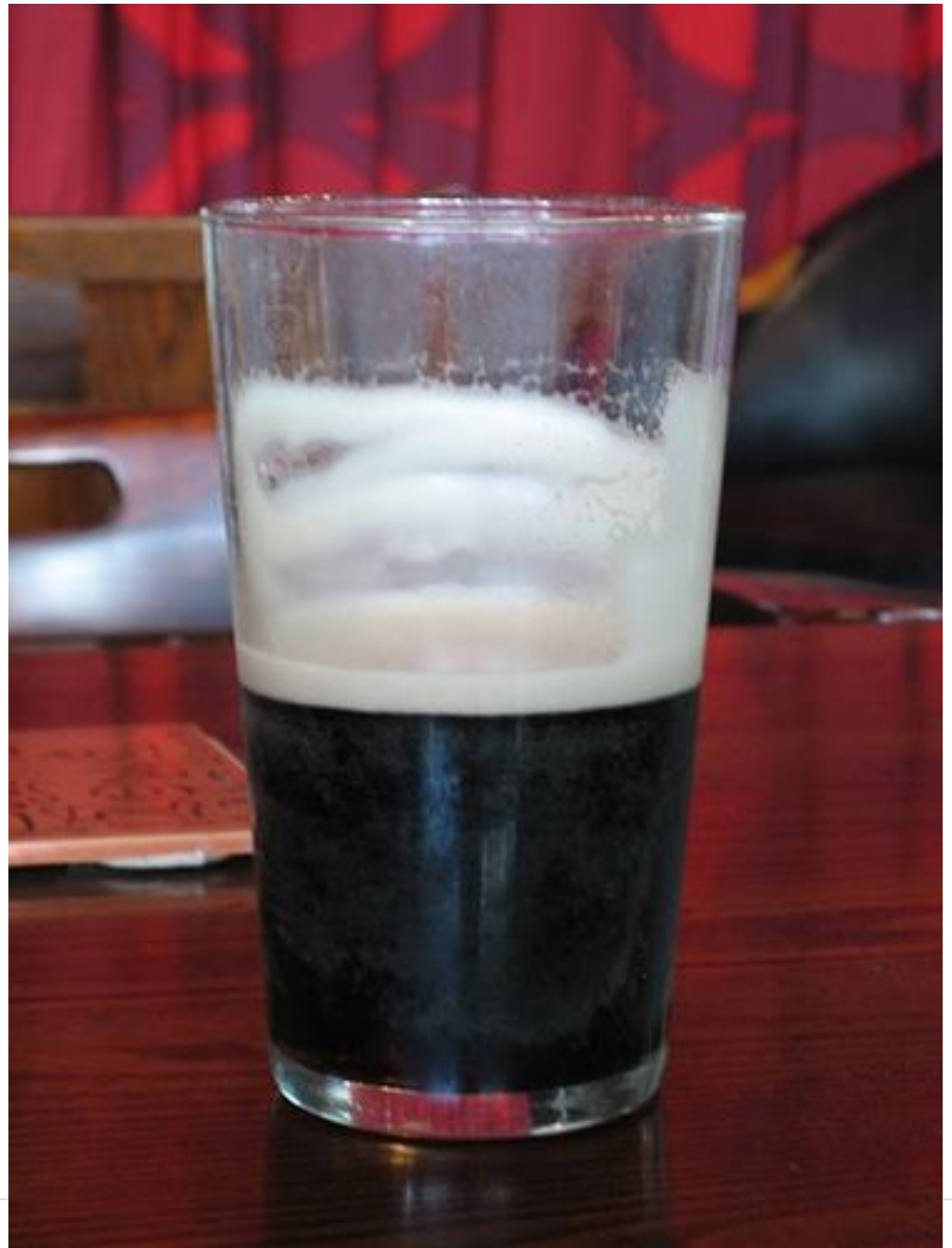
Improved participation for communication partners

- **Communication**
 - No longer need to write notes, make phone calls etc on behalf of CI user
- **Travel**
 - Able to go on long journeys
- **Interpersonal interactions**
 - Improved relationships with less conflict
- **Community, social & civic life**
 - Able to pursue independent interests

I had always been used to him being, because I had been ill myself, used to him being the stronger one of the partnership and then *I have had to be the very strong partner in it and in a way it is very good* because it makes you realise that you have both got vulnerabilities and strengths that you did not realise were there. So, in a way *I am glad that he is vulnerable as well* to some extent because I have seen that side of him that I did not know had existed after 20 odd years.

I am probably more tolerant than I used to be, you find a tolerance that you did not know you had. We have probably found out more things about ourselves in the last 10 months than we knew existed before. You know inner feelings that we had, you probably don't voice normally but you think well I will just, you know. *The things that were important before suddenly don't seem as important as they were.*

A glass half empty



A glass half empty

or

A glass half full?

