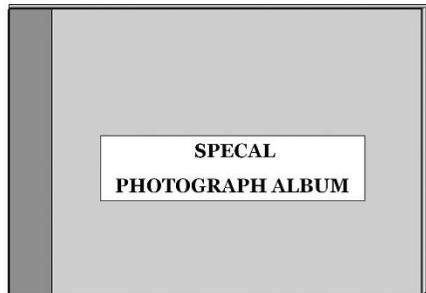


Appendix 1

To be read in conjunction with the response to the Mental Health Foundation Inquiry

My response to the questions posed by the Mental Health Foundation in their investigation ‘Dementia – what is truth?’ relies on the reader sharing my understanding of the SPECAL Photograph Album analogy (set out below) which underpins the SPECAL approach and method.



The analogy of a photograph album is used to describe, in a very simple way:

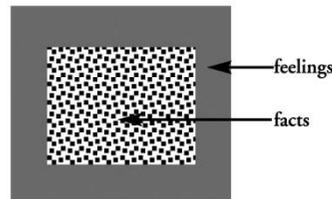
- how normal memory works
- the impact of ageing
- the single dramatic change that occurs with the onset of dementia

Within the analogy, the ‘photograph album’ represents our memory storehouse, with individual memories represented as ‘photographs’.

Each of our experiences in life is recorded as a photograph and stored in our album.

Each photograph has two features, facts and associated feelings:

FIG.1



Photographs are stored in our album a split second after each experience, and this storage requires no effort from us whatsoever.

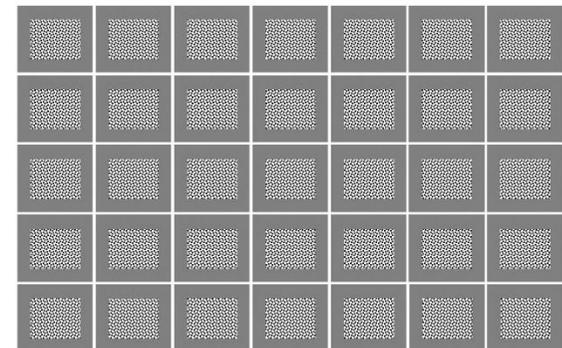
The taking and storing of photographs is a continuous, automatic and unconscious process going on in the background of our life, unobserved by us and unobservable by anyone else at the time of storage.

Our album falls open quite naturally at today’s page, where the latest photographs are arriving, so that we can constantly check what has happened in our life just moments ago.

This provides us with the context we need all the time for what we are doing, who with, where, when and why.

Every time we say ‘Now, let me think ...’ we mean ‘Let me look in my album’:

FIG.2



As we age, there is no change in the way in which photographs are taken and stored, but we become progressively slower at finding the photographs we need.

The photographs are there, but sometimes we are so slow in finding them that the moment has passed. Of course, as eyesight and hearing diminish with age, we may have less detail in our album than others expect us to have; we only store what we have actually experienced.

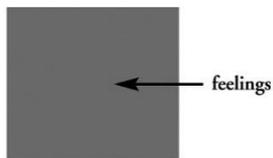
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Dementia introduces an entirely new type of photograph: a photograph in which the facts of what has just occurred are not stored, though the feelings associated with the missing facts are stored.

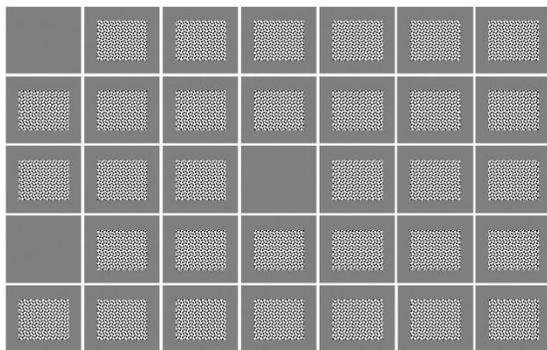
We call this new type of fact-free, feelings-only photograph a 'blank':

FIG.3



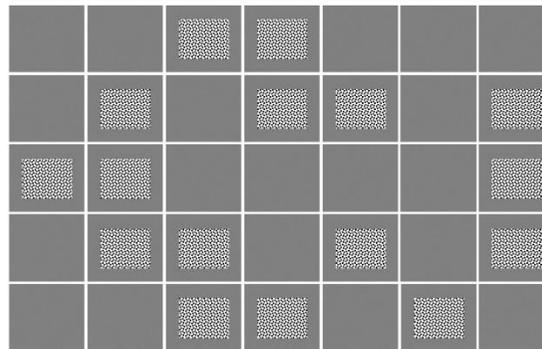
At first there are very few blanks....

FIG.4



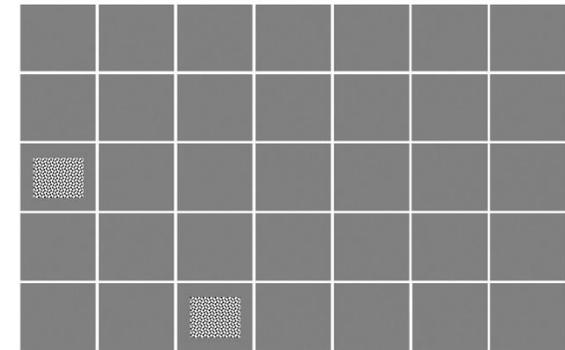
.... but they increase in frequency and gradually form long ribbons of blanks, dramatically altering the appearance of today's page in the person's album.

FIG.5



With time, feelings become much more important than facts for the person with dementia:

FIG.6



As the person possesses ever fewer facts about what has just occurred in their life, they will have increasing difficulty making sense of their surroundings as they consult their today's page – the page on which we all rely for immediate factual information about what we have just been doing.

There is a huge change here for the person with dementia, who has not lost their reason, merely their recent facts.

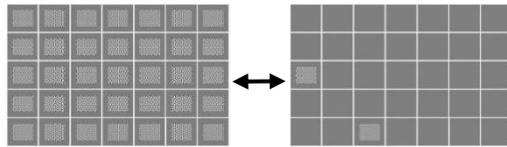
They will very reasonably turn back to much older pages in their album to find a useful match between what is happening in their life in the immediate present and their photographs from pages way back in their album, from the days before dementia – photographs which have facts and feelings in the normal way.

Appendix 1

To be read in conjunction with the response to the Mental Health Foundation Inquiry

Their normal reference point has changed, and they are adapting to the change in a way which we simply must understand.

FIG.7



This matching of old photographs to new situations enables the person living with dementia to compensate for facts which they need in the present and which are missing on their today's page.

The process of matching becomes an essential part of their life: a change from their previous norm. There is a growing difference between the person living with dementia and the rest of us: whilst we continue to have access to a coherent factual database of what has just been happening, they are progressively unable to do so. They have to work in a very different way from us, moving back and forth between today's page and pages from long ago.

Their today's page still provides them with a database of information, but it is a database with an ever increasing emphasis on the feelings of what has just occurred, without the accompanying facts. Their capacity to store feelings is increasing all the time, as they become progressively less cluttered with new facts on today's page.

Feelings become more important to them than facts.

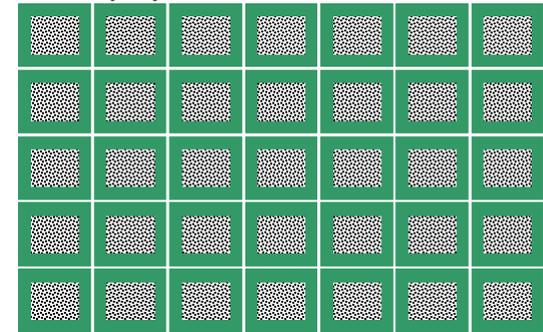
Bearing in mind that feelings store for everyone, we need to consider feelings in more detail.

We have divided feelings into two very simple categories: they are either OK, acceptable, feelings or not OK, unacceptable feelings. Acceptable feelings are coloured green; unacceptable feelings are red.

Most of our feelings in life are green: they are OK. Not amazing, necessarily, just OK.

So a normal album will look predominantly like this:

FIG.8

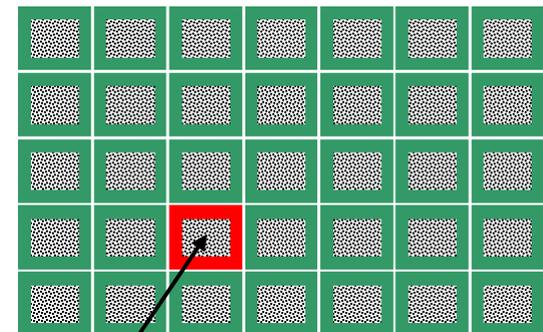


But every so often, in anyone's album, there will be a very occasional, unbelievably rare but nevertheless there, red.

Wholly unacceptable, deeply traumatic red.

Think of the triggers for post-traumatic stress disorder – that is what we mean by red.

FIG.9



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To be read in conjunction with the response to the Mental Health Foundation Inquiry

Example: the day the favourite dog got run over in the road outside the house - **RED**

We have to do something when red has entered the album.

Red is by definition wholly unacceptable, and an unbelievably powerful mechanism comes into play which drives us on to take action of some sort in response to that red.

We simply must make some kind of active response to a red in order to address our sense of outrage, pain or grief.

Example: deciding how to tell the children, burying the dog - not great, but qualitatively quite different from that red.

In the taking of action in response to red, green returns to the album and life continues on green.

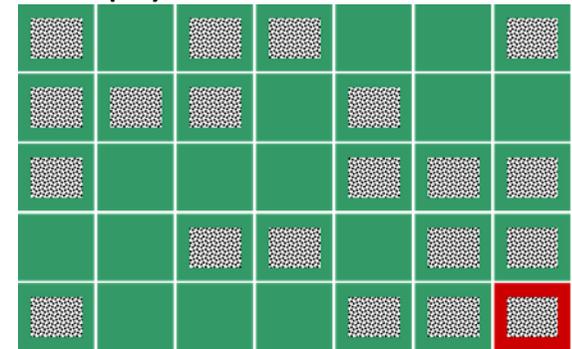
That red will always be there in our album, but since our life is generally on green our searching is also on green.

If we happen to come across an old red in our search for green information we will simply go round the red. We don't deny it is there but we are on a green search for green information and we no reason whatsoever to focus on red during our search.

That is how, without dementia, we handle the very occasional reds in our album.

Now let us introduce colour into the album of a person with dementia.

FIG.11



This is a page in the album of Dolly who is living with dementia at a stage where the blanks are beginning to occur sufficiently frequently to produce ribbons of blanks, representing blocks of lost factual information on today's page.

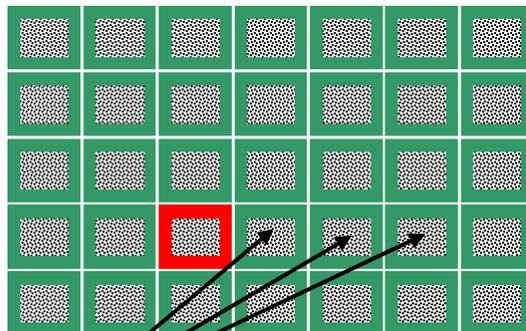
The red represents trauma, but we now have to consider the potential for an entirely new cause of red for Dolly: one which simply does not exist for the rest of us. It is crucial that we fully comprehend this key characteristic of dementia and its consequences.

There is a change here from our own norm, which we simply must understand.

Dolly's husband asks her to post a letter; she agrees and tucks it in her handbag ready to post later on.

Unbeknown to Dolly or anyone else, that conversation with her husband stores as a series of blanks.

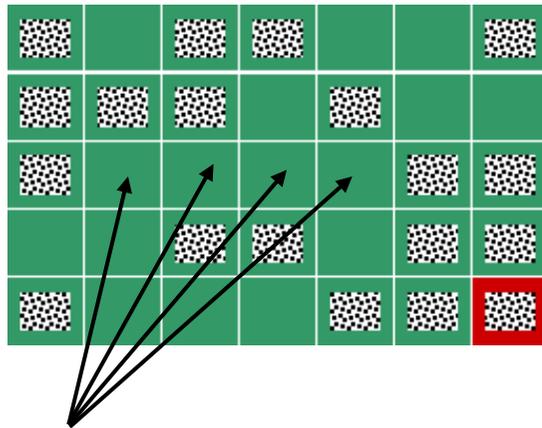
FIG.10



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To be read in conjunction with the response to the Mental Health Foundation Inquiry

FIG.12



Example: sequential blanks relating to the conversation about posting a letter, when Dolly placed the letter in her handbag. The red represents trauma for Dolly unwittingly caused by her husband later in the day.

It is important to bear in mind that the arrival of any photograph in the album, whether normal or a blank, is unobserved by the person and unobservable by anyone else, at the time of storage.

The conversation about the letter is OK, acceptable, to Dolly, as is her entire day.

The photographs on today's page are green, until, at the end of the day, Dolly's husband asks her, 'Did you post the letter?'

Dolly duly consults her album for information but can find no facts relating to a letter, and replies, very reasonably, that she has not posted a letter.

Her husband asks 'why not?'

Dolly checks today's page of her album again and explains patiently that she did not post a letter because there was no letter to post, but he insists that he saw her put the letter in her handbag.

Dolly is beginning to get quite cross – she knows he is talking nonsense. What is his problem? Has he gone mad? She opens her handbag to show him that there is no letter, and then....she finds the letter.

The shock is hideous – how can this possibly be? She checks her album again – it has completely let her down in a way that has never happened before. Her husband's album contains information about her activities which she herself does not possess.

Trauma of an immense magnitude for Dolly - how could he own information about what she has been doing when she does not own that information herself? And how much other

information might he or anyone else possess in the same way, without her even knowing?

This trauma for Dolly is something unknown to the rest of us.

Dementia is about the arrival of blanks in the album - they arrive unconsciously and are therefore potentially benign, yet the subsequent actions of other people have the capacity to cause trauma on a massive scale.

It is likely, in the relatively early stage of dementia, that this trauma will store in Dolly's album as a normal red, containing facts and feelings. Dolly can therefore identify what that new red is all about and respond in the normal way to the powerful mechanism that will drive her forward to take action of some sort so that green can return to the album.

In other words, Dolly has the facts of the cause of the trauma to guide her actions as to what to do next. The normal coping mechanism applies.

But dementia - the unconscious storage of blanks - is a progressive, irreversible

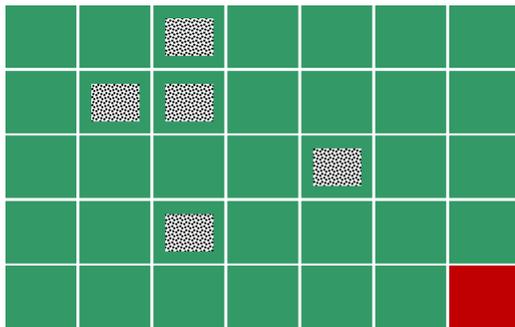
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condition, so what happens when the blanks build up?

As the blanks build up, any new trauma caused by being confronted with incontrovertible evidence of the existence of previously stored, potentially benign, blanks, will be increasingly likely to store in the album as a red blank – feelings with no facts attached.

FIG.13



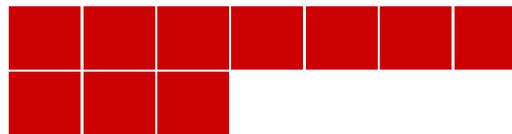
Now, when Dolly catches sight of a new red that has arrived in her album, she will know that something traumatic has occurred in her life, but will have no facts to explain the cause.

The normal powerful mechanism that comes into play in response to red will drive her

forward to take action of some sort but, without any facts, she has no idea what action to take.

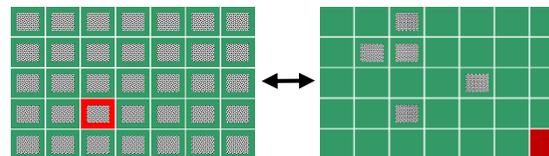
She is blocked and inevitably becomes jammed on red, with each moment creating a new sense of unprecedented internal panic which she cannot resolve.

FIG. 14



Dolly has not lost her reason, merely her recent facts, and she will, very reasonably, turn back to the pre-dementia pages in her album in a desperate search for an old red, one with facts attached, so that she can 'match' red to red,

FIG.15



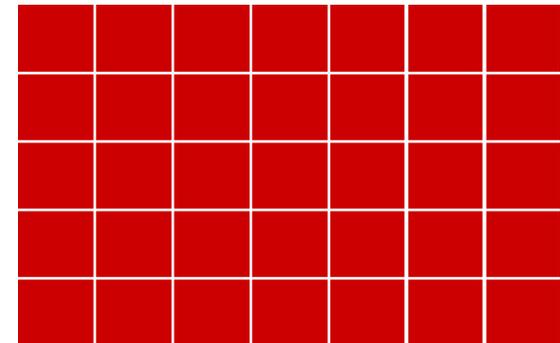
She can use those old facts to enable her to take appropriate action in the present, so that life can return to green.

But by now Dolly is completely out of sync with everyone around her.

She is talking about a dog to be buried, about her children, whilst her carer is trying to get her to sit down and have a cup of tea.

Dolly is in an intolerable situation and her behaviour will be in sync with her internal desperation as she is overwhelmed by insoluble distress.

FIG.16



She is being driven to the limits of sanity, not by the dementia but by the failure of others

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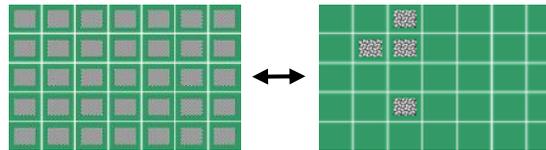
- who question her about the recent past (about which she has so few facts);
- who expect her to store the new facts they give her (when that is precisely her disability);
- who create havoc in her life by confronting her with evidence that they know more about her than she does herself;
- who do not understand the way in which she is having to match old to new;
- who unwittingly deprive her of her capacity to cope.

This caring response, this approach to ‘truth-telling’, takes no account of the person’s disability and is responsible for creating devastating behavioural change and apparent loss of personality and capacity for the person living with dementia.

BUT IT DOES NOT HAVE TO BE LIKE THIS...

We need to adapt our normal rules of communication and engagement, and reframe the concept of what truth and falsehood are all about within the framework of the SPECAL Photograph Album analogy.

FIG.17



There is a moral imperative to ensure that Dolly is always on green in the present, and then all her matching will be green to green.

We cannot stop blanks arriving in the album of a person living with dementia, but we can ensure that all new photographs are green.

We do this using SPECAL skills and techniques which both take account of the dementia and work positively with it.

The first step is to follow SPECAL’s Three Golden Rules:

1. Don’t ask direct questions – the facts the person needs to answer them may not have been stored
2. Listen to the expert – the person living with dementia – their statements and questions are highly significant
3. Don’t contradict – don’t argue with them about the photographs they choose to use

These rules may run counter to the common sense we all use when communicating with each other, but are tailor-made to improve the quality of life of the person living with dementia and will be found to have immediate positive impact.