

Arts4dementia

**D-IAGNOSIS!**  
*From Despair  
to Desire*

Jane Frere, 2019, pastel

**All images © Jane Frere**



Supported using public funding by  
**ARTS COUNCIL  
ENGLAND**



# D-IAGNOSIS! – *From Despair to Desire*

Over 200,000 people in the UK are diagnosed with a dementia each year. There is no cure for this range of degenerative brain disorders. But there is a global body of evidence that engaging with cultural and creative activity on a weekly basis can empower people to preserve their brain health.

In 2009, the New York Museum of Modern Art published its MeetMe programme for people with early stage dementia and their carers, which has had global repercussions, not least Arts 4 Dementia, the charity founded to help develop a learning stream for arts venues – across wider art forms - to re-energise and inspire individuals and their family carers to override the early strains of dementia. These programmes gradually became acceptable in Britain and around the world as post-diagnostic support. By this time, people will have endured months, sometimes years of increasingly lonely strain as symptoms set in, leading to loss of confidence, fear of failing memory assessment, of stigma and of the diagnosis itself.

The NHS introduction of social prescribing linkworkers to whom GPs can refer patients to address their non-medical, social needs, their interests, what matters most to them in life, inspired Veronica Franklin Gould, founder of Arts 4 Dementia to campaign for social prescribing to weekly arts to be offered to people at the onset of dementia symptoms. To support the campaign and encourage the health and social care services to refer patients to arts, she sought a campaign image, to hang at museums as a backdrop to cross sector meetings around the nation and inspire people with early symptoms to express their thoughts, in art.

The art activist Jane Frere was exhibiting her response to the strife aroused by Brexit [\*EXIT – 100 Days of Khaos\*](#) at Summerhall, in the Edinburgh Fringe in August 2019. Meeting the artist, mesmerised by the power of her vision – Frere had also nursed her mother throughout her journey with Alzheimer's, Veronica felt compelled to commission her to create an image - to demonstrate how culture and creativity can override the strains of dementia.

Their months of dialogue – about the length of time from onset of symptoms to diagnosis – 70 pages of emails, Frere's blackboard studies, infused by NHS politics, testify to their joint fervent campaign. The picture, a large pastel, launched at Tate Exchange, hung at three museums: The Beany House of Art & Knowledge in Canterbury, The Holburne Museum at Bath and The Wallace Collection in London before coronavirus hit, after which it headed Arts 4 Dementia's campaign at cross-sector meetings around England, Scotland, Wales and Northern Ireland and the Arts 4 Dementia Best Practice Conference, 'Arts for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia', on 20-21 May 2021, addressed by 90 leaders in culture health and wellbeing.



Jane Frere

EXIT – 100 Days of  
Khaos

2019, pastel

Summerhall Library,  
Edinburgh

*VFG to JF, 26 August 2019: Your campaign is the most powerful expression of the calamitous situation we find ourselves in ... Can I interest you in creating an artwork contrasting the inner turmoil, angst, stigma, fear, horror, bewilderment of a dementia diagnosis with the explosive inspiration of the arts that can light up the first few years of an otherwise devastating life?*

*JF to VFG, 26 August 2019: 'EXIT – 100 DAYS OF KHAOS! And the cliff edge of dementia diagnosis and explosive effects of arts that can prevent us hurtling into the abyss: I need to take a deep breath and take myself back into Mum's world ... My way into a subject is through emersion, then something clicks and I'm off !!!!*

## A4D participants say:

- *Living alone and being an elderly gentleman, I come here and draw again. I have put myself out to do something positive.*
- *I'm beginning to feel like a whole person - it's a real booster, makes it easier to socialise*
- *It's being part of something again*
- *Carer, You are thinking and not worrying*
- *I'm learning a new skill. It's uplifting.*
- *I enjoyed being expressive as well as creative - I'm rejuvenated!*
- *It's opened a door. I'm looking at art as I've never before.*
- *Carer, You have science and art working together and give it a new dimension really. I feel energised by it.*
- *It's broken my exclusive tendency.*
- *Being reintroduced back into a creative mind-frame, to meet people with the same mind-set has been an enormous help . . . it is exhilarating!*
- *You learn so much about life in art.*
- *Carer, You can't find a cure, but the next best thing is having this support. My enthusiasm is unbounded.*
- *It's inspirational. You feel involved.*
- *Granddaughter, Getting older people into modern art is great.*
- *You don't have to speak to express yourself*
- *I have dementia, but I also have a life*
- *Flying free as a bird around the studio, you forgot your troubles*
- *I was astounded to have dancing in me. I'm rediscovering my abilities and my balance.*
- *The music and laughter - my idea of heaven*
- *Carer: Mum leaves energised. One would expect her to be tired, but she is active.*
- *When I'm doing it I don't have time to worry about my memory. I do get frustrated though, My learning process here has been invaluable.*
- *I must try and experiment.*

**VFG to JG:** *The head and its angst, fear of loss of identity, stigma etc and contrasting transformative effect of arts – with undercurrent waves of dementia.*

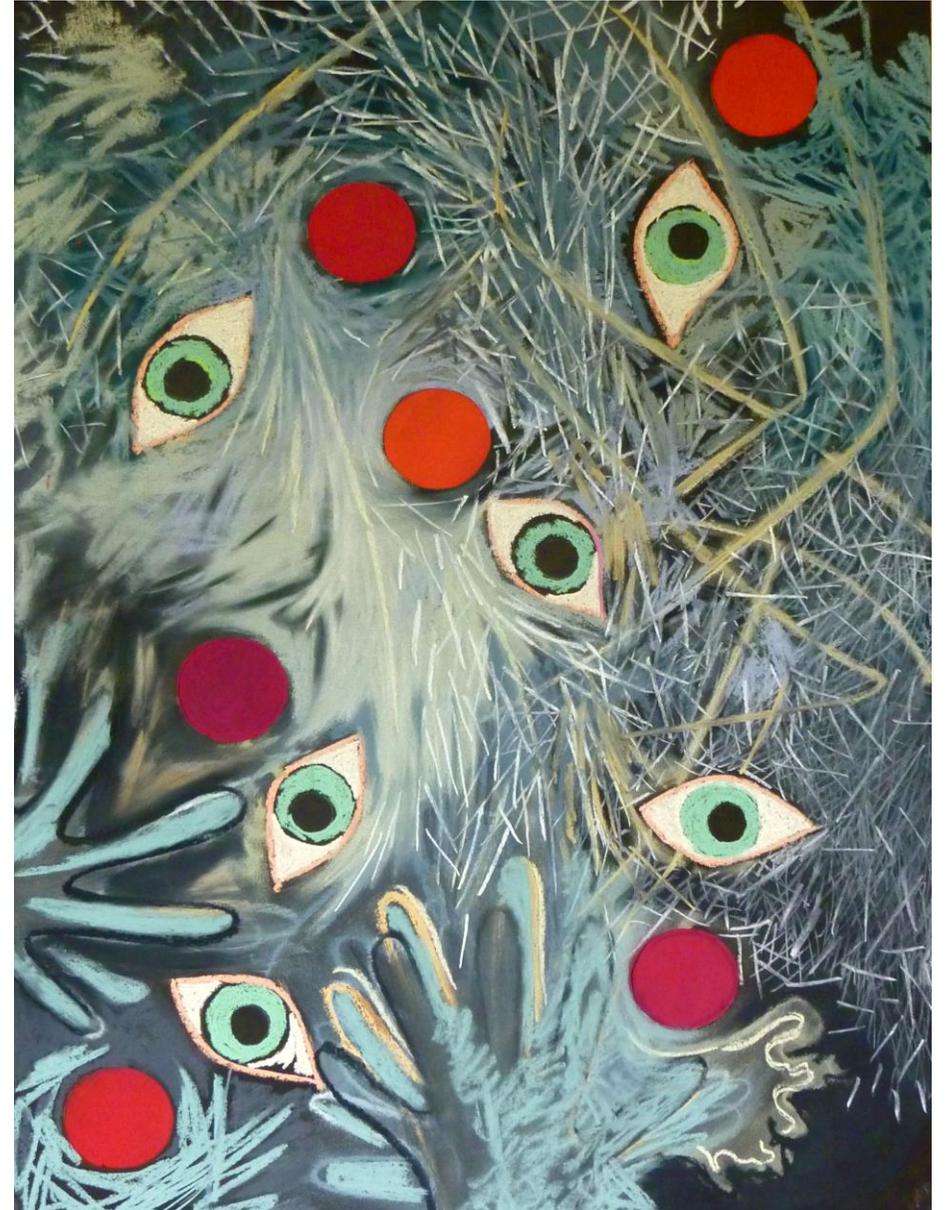
**JG to VFG:** *A work that can make an impact on a wide and varied audience: the NHS, GPs, social prescriber linkworkers, care services, arts organisations who run programmes for dementia, families affected by dementia – and the general public.*

*The overall shape will be a head, but to form a face all sorts of things will be happening within. It will be a simple shape but not when you look closely. There will be layers, strands and openings, with words too. It will have phenomenal reds and cadmium orange in it, so yes explosive colour.*

*Just to be sure, are you suggesting two heads in a landscape?*

12 September 2019

JF to VFG, 13 September 2019,  
*Revisiting pastels I did in 2010.*



VFG to JF, 29 September 2019

*Really as a campaign, to hang at a gallery, to achieve the impossible? - policy change – arts on diagnosis.\**

**JF, 2 October 2019 - The aim and concept of the work:**

The image stylistically Abstract Expressionism is comprised of two parts:

- A semi figurative head shape on left of picture depicting the tumultuous emotions of angst, fear, horror, bewilderment and stigma of a person's inner turmoil having recently been diagnosed with dementia in juxtaposed link to:
- A contrasting image of an expression of joyous celebration of ART (generically) alluding to a range of arts through motifs, shape, form, texture and vivid colours. The aim is to draw attention to the vital need to change the diagnostic process, offer arts at the same time as traumatic diagnostic testing - before diagnosis. Placing emphasis on the ability of art art through interaction and participatory practice to uplift and empower, re-energise and inspire hope and therefore well being at the most crucial time of diagnosis.

\* **VFG adds** *D-IAGNOSIS!* headed A4D's museum-hosted campaign meetings between regional leaders in culture health & wellbeing around the nation 2020-2021, to help advance social prescribing to arts on the point of referral to memory assessment.

# Notes on the Studio Wall

## JF to VFG

Aha! "What is the colour of shock? She asked "Cadmium red".

I use that red that you love to shock! It's impactful. It strikes at the heart. I use it very strategically, even when I worked in theatre. I will use it again, it may surprise you!

11 October 2019

**GREY 34**  
GREY 33  
GREY 4  
GREY 5  
GREY 3  
GREY 6  
GREY 12  
GREY 8  
GREY 9  
GREY 22  
GREY 27  
GREY 28  
YGE 16  
GREY 17

**11/10**  
THE BRAIN  
86 billion nerve cells  
each gain 10,000 more  
connecting to 10,000 others  
nerve cell death and  
tissue loss -  
BETA-AMYLOID PLAQUES,  
PROTEIN TAU, LOSS  
CONNECTION BETWEEN CELLS  
AND INFLAMMATION,  
10/10

LEFT hemisphere RIGHT  
HIPPOCAMPUS - long term memory  
objects & people  
MEDULLA OBLONGATA -  
involuntary functions - breathing,  
blood pressure  
CEREBELLUM balance, voluntary tasks  
reading, writing  
AMYGDALA - emotions/fear

"SELF" SOUL  
WHO AM I?  
WHO WAS I?  
ANOSOGNOSIA  
FRONTOTEMPORAL  
VERBAL SEMANTIC MEMORY IMPAIRMENT  
episodic memory  
semantic memory  
VERBAL MEMORY  
"HOW CAN I DICTATE TO MY FUTURE SELF?"  
SENSE OF SELFHOOD  
VISUAL SEMANTICS - A8

so many memories  
so many kinds  
so many cognitive impairments

dark shapes looming at  
you out of shrouded darkness

-A4  
BECOMING → UNBECOMING, TORN, BROKEN, LOST, CRUSHED  
-EMPATHY- WILL ALSO GO

"I am what I am"  
COGITO ERGO SUM  
I think therefore I am

DEHUMANIZED  
MADE LESS  
"them"  
no longer themselves  
gone - the mind - a brilliant mind  
now a sieve

MISSING  
"HORRIBLE DEGENERATIVE DISEASE"  
INCOMPREHENSION  
LIFE WITHOUT MEMORY IS  
NO LIFE AT ALL  
WITHOUT MEMORY - ADRIFT IN A HELPLESS PRESENT  
MEMORIES LIKE RESTLESS GHOST  
TERROR LOSING MEMORIES  
LOSING THE ACTIVE SELF  
WHAT ARE MEMORIES ANYWAY

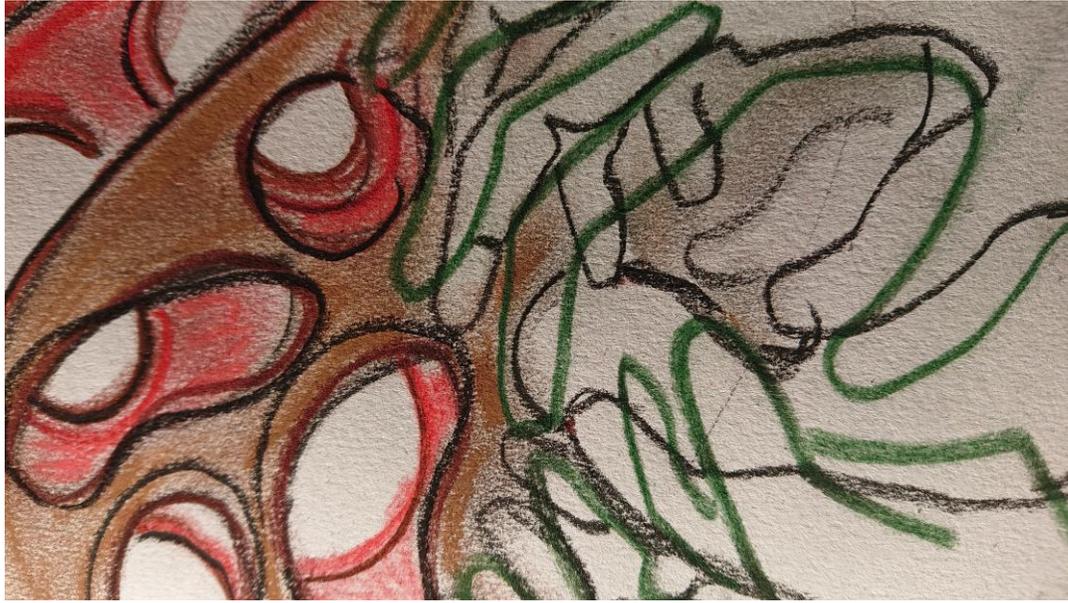
DE-CREATION OF SELF  
LOST  
DISSOLVED  
RECOGNITION FADING  
DISMANTLING THE SELF  
STRANDED  
FOG  
BEFUZZLEMENT  
GRIPLESS  
NOT ALL THERE -  
THEN WHERE?  
frailty, vulnerable  
dependent  
hope - less  
help - less  
decline  
defenceless  
powerless,  
victimized

TRUMA TERROR

Y7  
A13  
04  
A16  
Y3







## The Diagnostic Head

Sketch 1 (left),  
Sketch 2 (bottom left),  
Sketch 3 (centre)

*These are all very fast sketches, just getting a sense of eyes, hands, heads, they may or may not be used, but it gets me into the kind of image finally. They could be compiled as a block together for showing, as long as it's known they are preliminary sketches. I'll send more later once i've been through sketchbook. JF.*

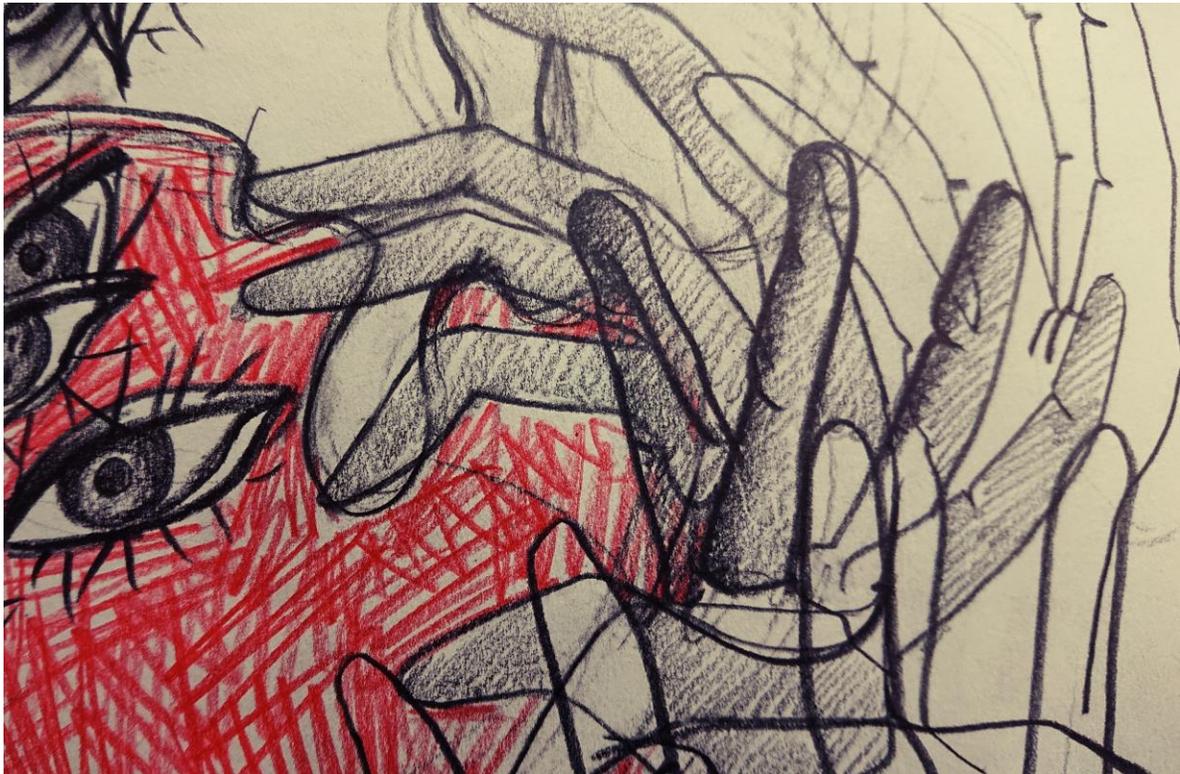


1 November 2019

Sketch 4 (left) Sketch 6 (right)

*These are examples of agonised heads. I'm looking at zig zag patterns, they create tension. JF.*

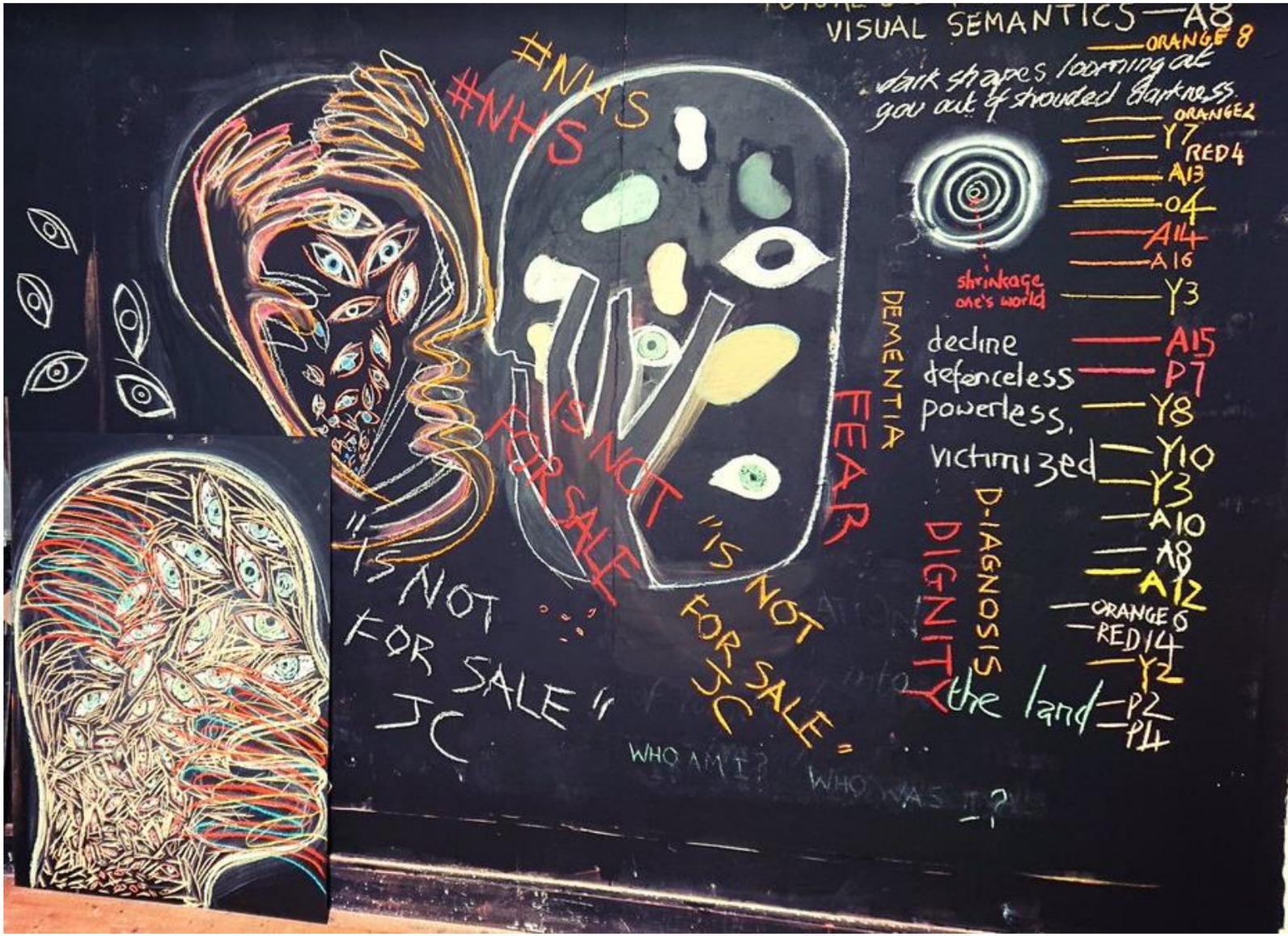
1 November 2019



The Diagnostic Head, sketch7

1 November 2019.

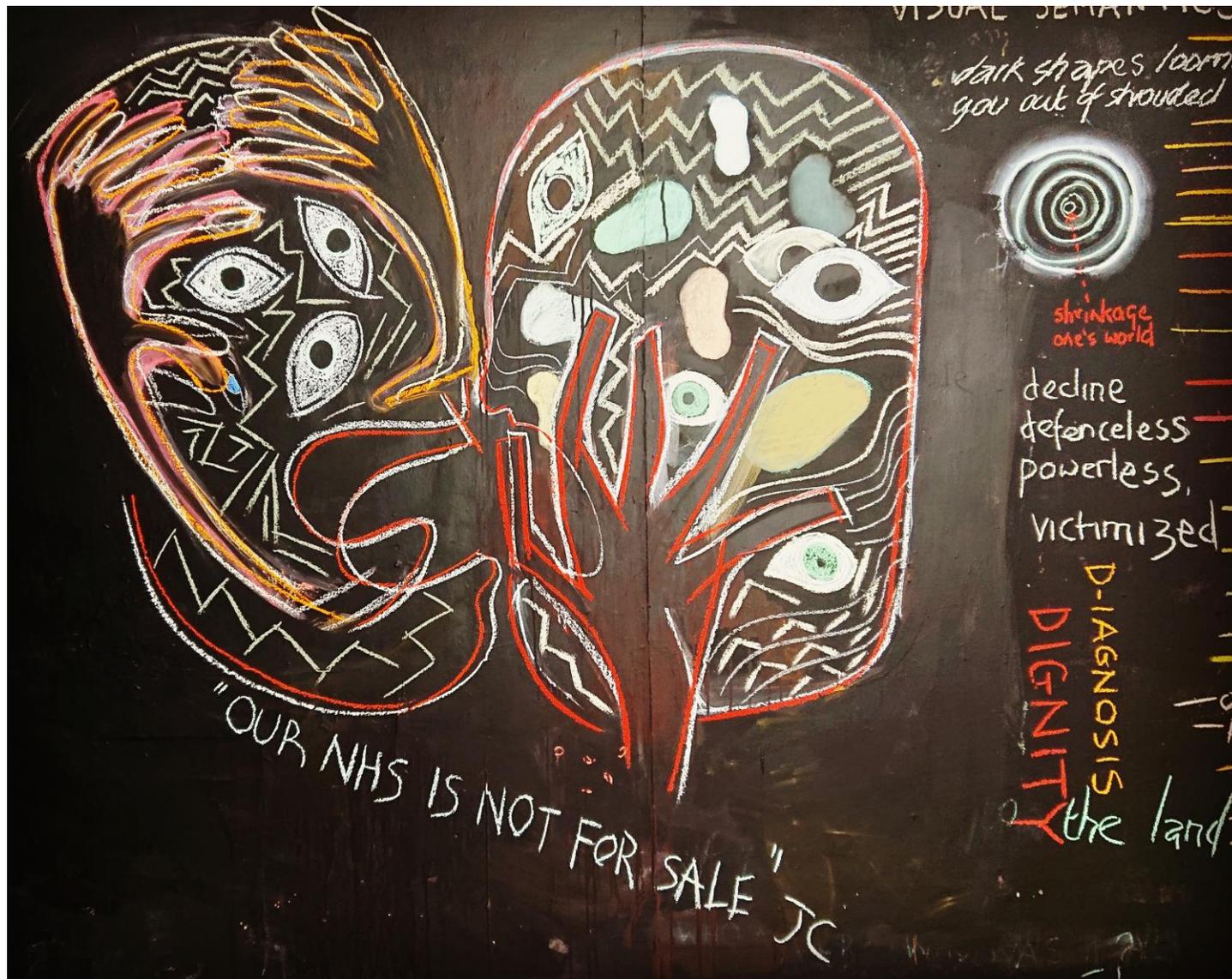




Dual profile begins.  
 'FEAR' 'DIGNITY'  
 'DECLINE'  
 'DEFENCELESS'  
 'POWERLESS'  
 'VICTIMISED'

JF, impassioned by  
 Jeremy Corbyn on BBC  
 Radio 4, inserts 'NHS is  
 not for sale'

1 November 2019



The first dual profile

3 November 2019

## JG to VFG, 4 November 2019

*I aim to have diametric contrast between the heads on both sides by using colour, the left head will be in a series of monotone greys graduating towards right head in full blast celebration of colour.*

*It's all coming together now at least and I'm glad you think it's moving in right direction because it was a tricky start. Well, these works always are. The images you see on the wall which is vast. I won't have space so many words. but will have key words none the less.*

*Maybe you could suggest some too: "fear" "fog" "self" "loss" etc*

*i need key words for the arts side, might I just write "dance" "joy" "release" "endorphin".*

## VFG to JG, 4 November 2019

*"I've got dementia, but it hasn't got me."*

*"Fear" "confusion" "too fast" "stigma" "lonely" "isolated",*

*"What's happening to my brain?"*

*"What will happen to me?"*

*"Will friends still talk to me?"*

*"Will I lose touch with life?"*

*"How will people understand me?"*

*"Will I still be me?"*

*"I can't explain - or can I?"*

**JF to VFG:** I like your idea of the eye in a state of fear moving /seeking a state of art.

Yes! The red waves may become arrows, so there is a very definite link.

I would like it to be two sides of same head, the hand touching comforting the one in state of peril. Quite a bit more to do getting colours right etc.

Words around the perimeter I think.

14 November 2019



VFG to JF, 24 November:

You have asked me to suggest short succinct words on the transformative effects of arts:

*Reawakening / Spirit / Identity /*

*Inspirational / Creativity / Resilience /*

*Valued / Expression /*

*Pleasurable / Enchantment / Joy /*

*Flourishing / Glorious relief /*

*Magical / Mystery / Imaginative /*

*Nourishing / Stimulating / Visionary /*

*Radiance / Harmony / Melody*

*Zest / Rekindle / Refresh / Revitalizing*

*Co-curating*



On the studio floor: Birds and hands express Fear vs Comfort. *Love, harmony, radiance, enchantment* and first musical instrument in *The Spirit of the Arts*, 28 November 2019

The artist's studio at night.

Hands, eyes, birds, waves of dementia, decorative elements explored.

28 November 2019





*I so shocked myself with the traumatised images that I have been creating, I decided the only way to combat this is with beauty, pleasure even if it's brief, isn't that the message of Arts 4 Dementia?*

*That space that offers reprieve from the space of turmoil in one's head? JF*

28 November 2019

**JF to VFG, 28 November 2019**

*All the bits you see are cut outs, I then place them in the face etc adding and omitting. I'm trying to keep the work from becoming too busy, too fussy, that negates its impact .*

*The words may not be so pronounced, I tried up side but didn't like it.*

*OK, a task for you .....*

*On left head I have the words Fear. Stigma. Loss. Lonely.*

*The right head represents a space where the spirit of the arts resides. A space for beauty, love, safety, refuge and enchantment, thus the beautiful birds and green leaves, a place of magic. I don't have the space for those words. So please can you give me your top 4 words..... They may not all go in but I will try.  
Enchantment is one!*

*Because I'm trying to say so much in one image, I'm hoping that simple elements, the two heads, the hands, the musical instrument can say it all. The harrowing birds of trauma, ravens of ill omen as opposed to birds of enchantment.*

*I'm thinking that if the work is used in seminars, I will give an outline statement for those leading , an explanation and perhaps a vocabulary of words can be used in that.*

*I do feel the work combined with explanation would benefit the events that it accompanies. Anyway as always I try to take on board what you say, but as mentioned, it's hopefully a work of art and so, I m challenged by composition, even getting the colours balanced etc.*

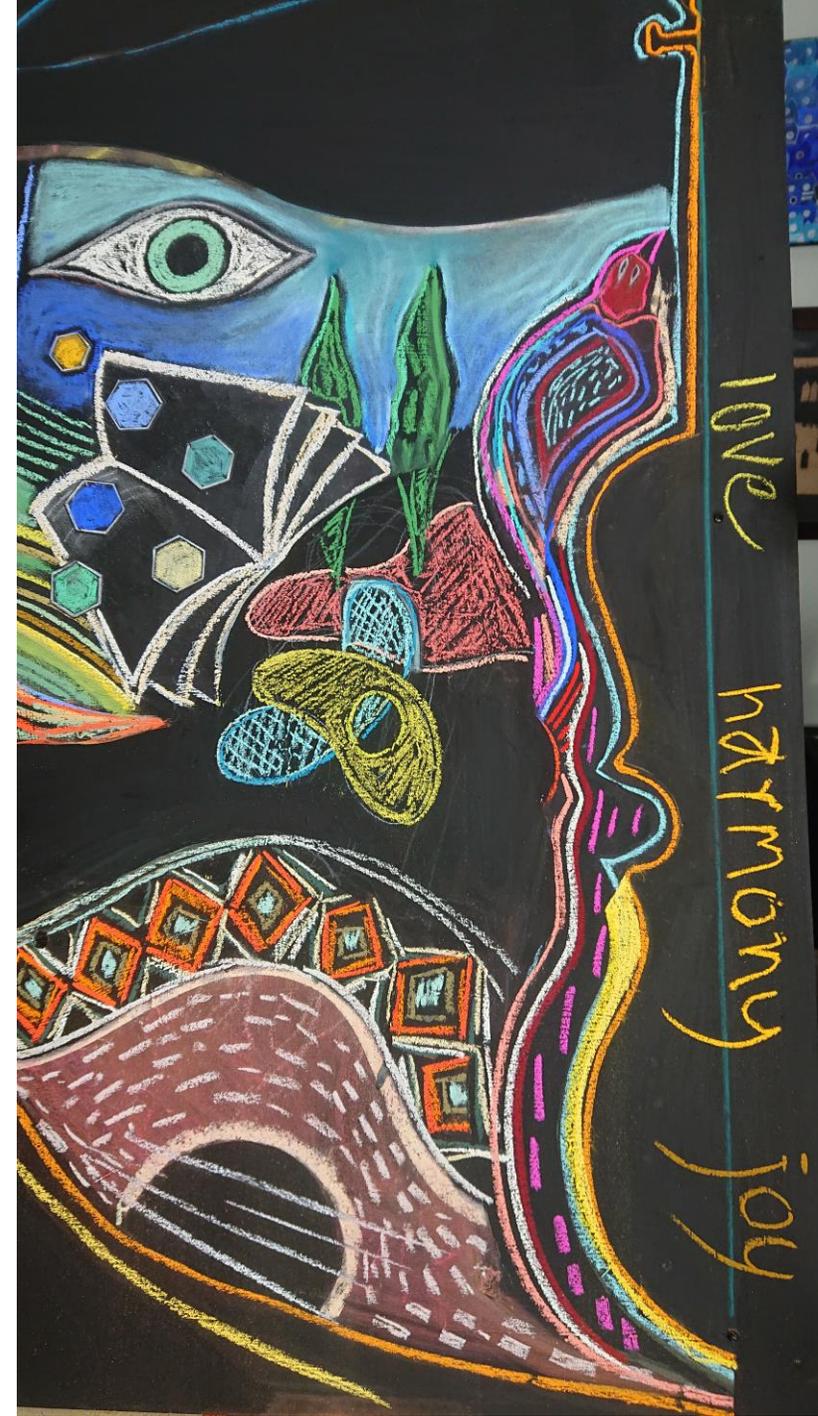


Words chosen by Keith  
Oliver, Alzheimer's  
Society Ambassador,  
for arts workshops:

Left: The Diagnostic Head,  
*Stigma, Loss Fear*

Right: The Spirit of the Arts,  
*Love, harmony, joy.*

29 November 2019



The Spirit of the Arts,  
with singing bird and  
lower stringed instrument  
recalling seventeenth century.

29 November 2019.





FEAR STILL HERE... LOSS

love harmony joy

*Fear  
Still Here  
Loss*

vs

*Love  
Harmony  
Joy.*

29 Nov  
2019



The first hint of an eye reaching out from The Diagnostic Head towards The Spirit of the Arts.

30 November 2019



Jane Frere

D-IAGNOSIS! From Despair  
to Desire

30 December 2019

Pastel, 1200 x 1000 mm

Launched at Tate Exchange, London, 9 January 2020, by leaders in culture, health and wellbeing, D-IAGNOSIS! shows a dual profile of a person agonised by fear of 'D' dementia diagnosis and transformed by arts activity. The Arts Head extends a hand of comfort to The Diagnostic Head, whose other eye swims over waves of dementia towards arts.

The picture, which hung at museums in Kent, Bath and London, fronted A4D's national campaign to advance social prescribing to arts from the onset of dementia, will be used to inspire people to relieve fear and preserve identity through artistic expression and the joys of culture and nature.