

need urgent help

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# Digitally Mediated Distress: Bodies, Affect and Digital Care

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Already got that sinking, preweekend feeling. I hate being alone in my flat, not knowing anyone in the area, I get so



At rock bottom and scared about how I'm feeling. Sorry to be moaning again but would love one day feeling ok



Thanks guys for all your encouragement last week. I was feeling pretty rubbish, but your 'love' kept me going and helped



www.elefriends.org.uk









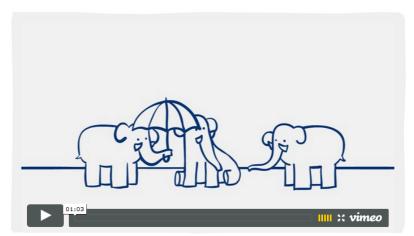








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Elefriends is a supportive online community where you can be yourself. We all know what it's like to struggle sometimes, but now there's a safe place to listen, share and be heard.





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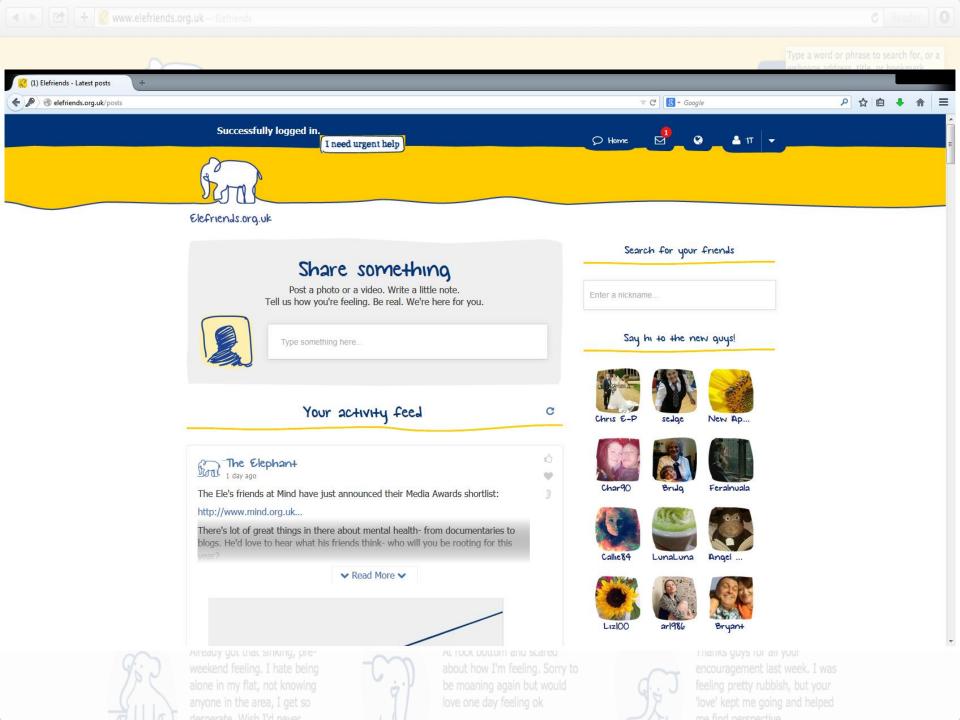
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## **Elefriends**

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- Elefriends indicative of the way that mental health services are become less tied to institutional settings
- Elefriends is moderated by a team of 'Ele-handlers' (although not overnight)
- The conversations that take place in the site are not always relating to a specific mental health experiences - sometimes people just talk about their cats for example
- Its uniqueness centres on it being managed specifically around the image of the Ele, with users adopting the identity of being an 'Elefriend'. In this sense Elefriends is not a 'tool' as such but a digitally mediated space for care and support
- Elefriends can be thought of as one of the most prominent technologies of connection in mental health communities
- Our concern is to understand how bodies are experienced when distressed in an online peer support space.



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## **Experiencing bodies**

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- Our experience of using technology (i.e. Elefriends) is delivered to us through our bodies
- Bodies are routinely disposed for action in particular settings (Mol, 2002; Munro, 2001)
- "to have a body is to learn to be affected, meaning to be 'effectuated', moved, put into motion by other entities, humans or non humans. If you are not engaged in this learning you become insensitive, dumb, you drop dead" (Latour, 2004: 205).
- Importance of recognising the body as movement as a source of unfolding potential for affective responses



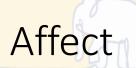




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- Affect present at the encounters between bodies in the form of an intensive set of feelings (Brown & Stenner, 2001)
- This feeling can be qualified as a recognisable emotion (e.g. fear or happiness) but cannot always be directly articulated
- Anderson (2010) affective atmospheres;
  - "indeterminate affective excess through which intensive space-times can be created" (p.80)
- The *atmospheres* that are continually being created in Elefriends (due to the digital encounters between bodies) require people to continually create their own potential grounds of experience the *art* of life (Brown & Stenner, 2009)
- Elefriends are continually enacting their role and activity in the site as well as being aware of and responding to how their body acts upon others (i.e. the collective)





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# Digital bodies

- "enframing information can be said to "give body" to digital data to transform something that is unframed, disembodied, and formless into concrete embodied information intrinsically imbued with (human) meaning" (Hansen, 2004: 12)
- The digital image is inextricably connected to the activity of the body in which information is made knowable in the process of moving into a digital space
- Populating an online profile with information works to give body to that information and in doing so invests an affective dimension to the digital image







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[Amy]"Wow! One year ago today I joined Elefriends. I will never forget that time. It was truly truly horrendous. I was completely and utterly alone. My therapist was away for a long time, my medication had been changed and wasn't suiting me at all, and the doctor told me to cope on my own. It was the time when I had no one to turn to and no health professionals were listening to me. I was searching and searching every day for some kind of support to get me through. Eventually I found this place. It wasn't easy for me to begin with. I worried so much about posting the 'wrong' thing and it coming back to haunt me later on. But slowly, slowly, I got used to the idea and it has been a real lifeline for me. Somewhere safe to say how I feel, without fear of judgment and without worrying that I'm letting people down. I can't believe how far I've come since that dreadful time one year ago, my complete rock bottom. I'm still up and down, I still had bad days, but it makes such a difference to be able to get my thoughts out of my head on here. Thank you Elefriends for always being there xxxx" (online)





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[Julie]: I think the way I felt personally at the time, I was searching for answers and I was literally just trawling the computer looking for answers as to why somebody would commit suicide. I looked on American websites. I looked on British websites. But when I saw Elefriends, I saw that there were people who, you know, were all walks of life, all, you know, ages, all types, if you like. And initially, I wasn't really looking for a mental health help for myself. Well, in fact I was, but at the time I was thinking of my son and trying to find answers, which as time goes on, you realise you're never going to find an answer to why someone's ended their life, really... And I didn't – I think I didn't appreciate the help I was getting really at the time. I think I was just searching, searching, searching (long pause) and using it every day and maybe speaking to people only if they'd posted about how they felt suicidal... as time goes on, you realise that your own mental health is affected by bereavement, in my case. I've suffered with depression in the past and I suppose, in a way, I've also used it to try and pass on my knowledge and my thoughts to others, rather than just taking – I'm reluctant to say help, but let's say help from other people. I started to offer my (long pause) – what's the word I'm looking for? Again, I don't like to say help because I don't know if you help anybody. But, you know, your experiences, a shared experience perhaps. (Interview)

# Emotive latency

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- "Emotive latency refers to the incompatibility between experiencing oneself as a subject as well as part of something greater than one's own individual self (i.e. the collective). Simondon defines emotion as latent as it remains so until transindividual relations take hold through processes that are always-already collective. This means that emotion cannot be entirely reduced to the level of the individual, however personal it may feel, but is always the product of processes that are collective." (Ellis and Tucker, 2015)
- Elefriends enacted through affective intensities in which strands of individuality and collectivity entwine and knot



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## Fragile care

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- [Sarah] "Every time I stumble across an account that has been deleted I find myself worrying about what could have happened to that person. What if they are not okay? What if I could have helped? Where have they gone? What if I disappear next? How can I find out how they are? Do the Elehandlers check on people?"
- Inactivity is a common part of social media use, and yet we see it takes a particular significance in Elefriends
- Prolonged periods of distance can impact on the rest of the community. These periods of disconnection can be unpredictable and erratic.
- Deletion as risk



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2.:-(

- 1.I know have been so worried about her but knowing she was here among safe & loving Elefriends meant I could try to support her :-( Does anyone know anything about her deleting her account? I'm just worried she's not safe :-(
- 3.:( Oh no~
- 1.Yeah I keep checking in case I got it wrong but it's definitely saying it's been deleted :-(
- 1. She had times when she said was going to leave as she didn't want to be a burden to anyone but she always stayed so it's a shock to see this. I wish I knew what to do to find out if she is safe. I guess it's a case of just hoping she is
- E.The Ele just wanted to pop in with some extra hugs. He knows that it can be a bit of a shock when an elefriend deletes their account. Sometimes an elefriend might decide that want a little time and space, but lots of people do come back when they feel more ready to chat. The Ele and his handlers are contactable by email elefriends@mind.org.uk if anyone has a question about their account.
- 1.Thank you Ele \*hugs Ele back\* I hope that is the case for blue giraffe & I respect her need for that. Just hoping she is safe is all thank you Ele xxx
- 1. Oh Rachel thank you so much! That's very kind of you grateful hugs xxx (IN RESPONSE TO SOMEONE OFFERING TO PHONE BLUE GIRAFFE)
- 4. So many people do disappear and we wonder why, alas it is the nature of our illness but people do return as well :0)
- 1. Hope so I just know she was in a bad place I truly hope she just needs some space & will return. I respect her decision it's just in my nature to worry xxx



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- "Caring relations require taking care of the on-going (affective) relations they create. Caring relations require caring about the conditions of possibility they enact. The unfolding realities of illness underline that our embodied selves, as well as our personal orderings, are fragile, on-going collective achievements of humans and things that need caring relations in order to feel at home." (Schillmeier, 2014: 12).
- Need to care for caring relations
- Ele steps in (brief) return to a paternalistic model





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# Ambiguities of digital care

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- Implications of power of social media being put to work in mental health communities
- Distressed bodies not pre-formed entities, but are subject to affective practices made possible by Elefriends
- Distressed bodies enrolled in new forms of care, that then need to be cared for
- Elefriends not just a tool for support, it's a space (and time) in which distressed bodies are enacted through entwined processes of individuality and collectivity in the unfolding of everyday experience





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