

**NEWSLETTER NO 24**

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**Interview with David Burgess – Chief Executive of Different Strokes since January 2004.**

As readers will be aware, the founder and former Chief Executive of Different Strokes, Donal O’Kelly, moved on to pastures new last year, and consequently, David Burgess was appointed to the role in January this year.

As the result of an accident as a young child, David has both physical and sensory disabilities and is thus acutely aware of the challenges facing stroke survivors and will be able to empathise with the problems and needs of our members. He has previously fulfilled the role of Chief Executive for organisations that support people with disabilities, and has recently been a Consultant for The Hearing Advisory Trust.

David is accompanied to the office by his faithful dog Bertie, a Cavalier King Charles Spaniel, who is also a trained hearing dog for the deaf.

**Q1. What attracted you to apply for the role of Chief Executive with Different Strokes?**

A. Firstly, I had an existing knowledge of Different Strokes, having met Donal O’Kelly back in 1995 at a Stroke Association Conference when I acted as a keynote speaker – and I was keenly interested in Donal’s dream and aspiration to create a supportive service aimed at younger stroke survivors. I like to think that I encouraged Donal in a small way to set up Different Strokes.

**Q2. What was your first impression of the charity when you attended your interview?**

A. I was greatly impressed by the tremendous enthusiasm and sheer commitment of everyone I met – Trustees, Staff, Volunteers, and stroke survivors themselves – all wanting to ‘make a difference’. I felt, from those early meetings, “This is my sort of Charity, and one I’d like to get involved in!”

**Q3. What major changes will be apparent to Different Strokes membership in the near future?**

A. I am not sure that ‘major changes’ would be appropriate for the Charity and its members in the immediate short term. I would like to firstly look at improving our ability to increase our current level of annual income streams, and thereby our human resources, to ensure that the level of core services we deliver now can be sustained. Once we have achieved that aim it would then be appropriate to look at possible new innovative services to enhance our existing ones. But again, this will require new

and additional funding to implement them. As a long term vision, I would like to see Different Strokes self-help Groups set up in every major town and city throughout the UK. Likewise, the name Different Strokes becoming known and respected nationally as the organisation specialising in quality support and help for younger stroke survivors.



**Q4. Will there be an opportunity for Different Strokes’ members to have a say in what services will be offered by the charity?**

A. I believe that the time is absolutely right to take the opportunity to seek the views of everyone involved in Different Strokes, and importantly, that includes our service end-users, known in DS as ‘members’. All too often organisations wrongly assume that what they are doing or delivering is right and needed, when in fact, perhaps it’s not! Also, we might look at setting up a proper national membership scheme, with the sort of attractive benefits such schemes can provide.

**Q5. How do you like to spend your free time; what hobbies or interests do you have?**

A. When time permits, which isn’t very often, I enjoy numerous hobbies and interests. I particularly enjoy attending 3-day equestrian events as a spectator, painting in either watercolours or oils, restoring antique furniture, reading and world travel.

**Q6. Is there anything else you would like to add?**

A. I truly believe that for Different Strokes – our world is our oyster. I personally look forward, as I am sure everyone else associated with Different Strokes will, to see our organization grow and flourish. It will not necessarily happen overnight. It will not be without difficulties to face and overcome. Undoubtedly, like many charities similar in size and at the same stage of development as Different Strokes, it will be challenging. But above all, it will be fun!

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**Different Strokes 2004 Annual Conference**  
**Saturday 21<sup>st</sup> February, York House, Twickenham**

Despite the cold February weather, it was encouraging to see over 90 attendees at this years Annual Conference held in Twickenham.

Maintaining the annual custom, this years conference host and organiser was the London West Group, lead by Julia Jenkins, and sponsored by Rugby Football Union. Our grateful thanks to them.

Julia opened the Conference with a brief introduction to the day's programme, and an insight into the history of York House and Twickenham.

Keith Wood, Chair of Different Strokes, presented the Trustees report entitled 'The Good and Bad News', which, despite its title, was very much upbeat and positive, looking to the ongoing work and challenges that lie before us.



John Horan — Trustee

David Burgess introduced himself, and gave a brief insight as to his initial impressions of the Charity, following his appointment as Chief Executive in January this year. He concluded by mirroring the Trustees' view that our first priority must be fundraising - to secure a financially sound and sustainable future for Different Strokes, and thereby, the stroke survivors we aim to assist.



Keith Wood — Chair of Trustees

First of the day's guest speakers, Robin Gargrave and Max Bower from YMCA, gave an animated and interesting talk entitled 'Why Exercise?', demonstrating how inactive we can be in terms of daily exercise. It gave us all food for thought!

Sheila Hale, wife of the late Sir John Hale, gave a moving talk about her experience of stroke through caring for her husband, and which ultimately, lead her to write her book 'The Man Who Lost His Language'.

Following a delicious lunch and a chance to renew friendships, Lynne Darnelle, a professional



Dr Pankaj Sharma

Counsellor, opened the afternoon session by outlining standard counselling referral processes, and the steps taken to provide suitable Counsellors when Different Strokes refer cases to her.

The Conference 'Medical Update' provided by Dr Pankaj Sharma was well received by all delegates. Outlining recent research findings and statistics, Dr Sharma reiterated the medical professions' move to rename 'stroke' to 'brain attack', claiming that statistics show that stroke is now second only to heart attacks as a cause of death in the UK.

Finally, to end the Conference, John Horan, a DS Trustee and Barrister, gave us an insight into his personal experience of disability discrimination; the 1995 Disability Discrimination Act; and encouraged delegates to act positively if they consider they have been discriminated against.

As delegates departed, everyone agreed that the day had proved both worthwhile and enjoyable.

## **BIONIC ARM**

The world's first clinical application of 'bionic' miniature neuromuscular stimulator implanted into the muscles of the arm is being developed by a multidisciplinary team of researchers led by Dr. Jane Burridge at the University of Southampton. This pioneering system will aim to control, through electrical stimulation, weak or paralysed muscles to produce functional arm and hand movement in patients who have suffered damage to the central nervous system following a stroke.

The research is based on the BION<sup>®</sup> microstimulator (Alfred Mann Foundation, Valencia, CA, USA) that once implanted into a patient's arm act like 'bionic neurones' mimicking the messages from the brain to produce functional arm and hand movement in patients who have central nervous system lesions such as hemiplegia following stroke. A BION stimulator is used to generate the electrical stimulation between the electrodes to provide the potential for fine control of movement in the patient's arm and hand. Each electrode is 'individually addressed' so each BION stimulator can be controlled independently to a maximum of up to 255 BION devices. The BION system is much less invasive than previous generations of neural implants and overcomes the cosmetic and donning problems of surface stimulation systems.

About 100,000 people suffer a stroke in the UK each year, and with increasing life expectancy, this number is rising despite better control of the conditions that make people more likely to have a stroke, such as high blood pressure and diabetes. Improved acute care also means that more people survive a stroke, but are left with a disability. About two thirds of people who have a stroke regain the ability to walk, but less than 30% regain useful arm function and research has shown that it is poor arm and hand function that leaves people unable to live full and independent lives.

Most patients undergo a period of therapy following their stroke and this usually includes physical activities aimed at improving arm and hand function, but conventional treatment is often not effective and Functional Electrical stimulation (FES) is becoming more widely accepted as an additional treatment. Electrodes, placed on the skin, conduct small electrical impulses from a 'stimulator' to the weak muscles making them contract and so move the limb. In small research studies this treatment has shown some improvement, but people find it difficult to place the electrodes in the correct place and it is difficult to control the stimulation to produce a natural, useful movement.

Because this is the first time BION microstimulators have been used in this way the project will be with only a small number of people, initially four BION microstimulators will be injected into four muscles that control opening of the hand and support grip. The system will be activated initially by a simple trigger and have no more than three phases enabling the user to open their hand, grasp an object and release it. During the second and third phases of the project we will extend the implantation sites to include the triceps muscle that extends the elbow to support a reaching movement. We will also develop a more sophisticated system using sensors to control the BION microstimulators so that movements are more functional and responsive to the patient's intentions.

The study will involve extensive measurements of movements, forces generated by stimulation, the effect on the activity of the muscles and people's ability to control their movement. We will also be measuring whether using the BION system improves their everyday arm and hand skills.

Ruth Etherington  
Research Fellow (Bion Project)  
University of Southampton

## profile

### MARATHON MAN

“We don’t know. You might do or you might not. Some people do walk again and some don’t. We will do our best and see what happens.” I started to regret admitting to two questions, but as there were only the two physiotherapists and me in the room, I could not pretend it was someone else. Asking if I’d be able to run again, sounded as stupid as I had belatedly realised it would.

It had started a week or so before, a beautiful crisp, cold sunny Winter’s day, the first Sunday of 2001. I had run a ten mile race over Epsom Downs, been given a lift home, showered, changed and set off down the road to meet my wife, Lynda and children, Laura, 10, William, 7 and Abigail, 3 at friends for lunch. Does it get any better?

As I cross a main road, there is a strange noise in my head. Shaking my head, I mount the pavement, but the noise does not go away. Then, I cannot control my body. Desperately, I try to cling to a bush, afraid I’ll fall into the road... I come to lying on the pavement, surrounded by a small group of kind people (including a doctor), who have seen me and stopped to help. An ambulance has been called and Lynda is summoned. We spend the afternoon at A&E at Mayday Hospital, Croydon. Nothing is found, but as I have banged my head and passed out, am told it would be best to stay at home for a day or so.

I follow the advice. On the Tuesday, Lynda, Abigail and I have just finished lunch, when the noise in my head starts again. Before I fall, I lay down on the kitchen floor. I start to throw up... I come round back in Mayday

Hospital, attached to tubes and a mask. My brother is by my bed, nice to see him, but why is he here? Probably to have his ears sorted out as he can’t hear, or at least understand, me very well. Still, he is doing better at that than the poor, attentive and caring, nurse assigned to me and he has to translate.

He says it is Friday. Later, I learn that in the intervening three days I have missed what Lynda, who is a doctor, describes as the hairiest and fastest ambulance ride of her life. I have been kept sedated but alive in ITU, while they try to find what is wrong with me. An early scan does not show damage to my



brain as I have been taken to hospital so quickly. Lumbar punctures and other tests precede another scan, which answers the question, showing the damage to my brain. It had not been clear I would r e g a i n consciousness when they stopped

the sedation.

Later, I am told I have had a stroke. What did I know of stroke at 42 and no family history? It happens to older folk and it is not very good – well, right on one count.

Some capabilities start to return, but my balance is badly affected. The physios start to get me to stand and then walk. A speech therapist arrives, but she recognises my returning South London mumble and lets me be. I try to write – ugh. The physios work hard and after three weeks I can get around enough to be allowed home.

The physio and exercise continue at home and as an outpatient under the talented care of physios and my GP visits regularly. Lots of

tests ensue to establish what happened. By elimination, my Neurologist concludes that my posterior vertebral artery dissected of its own accord.

Family and friends help keep the household and our young family moving and me occupied. Friends from all walks of life, at home and abroad, do not let up on me and the calls, cards and visits continue. A Chelsea season ticket holder, arrangements are made to switch my seat for the disabled section and I'm taken to my first game in a wheel chair. An incredibly patient piano teacher, with a large supply of cotton wool for her ears, gives me lessons, which help me regain control of my fingers. I am not left to myself.

I learn of Different Strokes and devour the Newsletter each time it comes in the door – a point of reference in an uncertain world. “Hey, there is a lady in here, who ran a marathon after a stroke.” Lynda gives me an old fashioned look, but after a few months I rather gingerly start running again – fantastic.

Citigroup, my employer (especially my immediate managers), is wonderfully supportive throughout. After 9 months, I return to work part time, under the careful control of the outstanding company doctor and his occupational health team. It is great to be back with friends at work.

Life begins to return to a more normal pattern, but I still regularly get very tired. When I do, I am clumsy, irritable and have to concentrate very hard on the things the physios taught me. Maybe if I can get fit, I will overcome the tiredness. I have been managing one gentle run a week, which I gradually extend. After some months I join a very friendly running club, Striders of Croydon, which really helps. I am fitter, but the tiredness does not go away.

The weekly run is extended to the point where, in September 2003, I enter a marathon in London's Battersea Park. It is quite a small park and so the field of about 80 complete the 26.2 miles over 15 and a bit laps of the Park. 3 hours and 45 minutes later, the family, friends and employer who have been so supportive of me, have contributed over £11,000 to Different Strokes.

Nearly three years after the stroke, I am doing well. I am still working part time under the care of the occupational health team. I continue to get monumentally tired and am then still clumsy and irritable.

I have been incredibly well looked after and cared for, but also I know I have been very lucky.

**Geoff Pennells**



## NEWSLETTER BY E-MAIL

**Would you like to receive future issues of the Newsletter by e-mail?**

If so, send an email to:

**[newsletter@differentstrokes.co.uk](mailto:newsletter@differentstrokes.co.uk)**

and we'll put you on the electronic mailing list. If for any reason you change your mind in the future we will happily revert to using 'snail-mail'.

**REGIONAL COORDINATORS**



Different Strokes have vacancies for three REGIONAL COORDINATORS to establish, support and coordinate Different Strokes local groups/exercise classes. One person is required for the Anglia Region, one for Wales and one for Northern Ireland.

**The person must have:**

- knowledge of issues concerning stroke survivors
- knowledge of setting up new projects
- personal experience of stroke
- skills in managing a team
- the ability to project a corporate identity



**The post holder will be responsible for:**

- setting up local exercise groups throughout the area and ensuring they operate to the standards set out in the Different Strokes Charter
- the recruitment and induction training of Volunteer Group Coordinators, enabling volunteers to start local Different Strokes exercise groups
- arranging and presenting training for Volunteer Group Coordinators
- collating local statistical information as required by head office

If you have these qualities and experience of managing projects either in the statutory or voluntary sector, write or email for further details and a job description to: Anne Barby, Different Strokes, 9 Canon Harnett Court, Wolverton Mill, Milton Keynes, MK12 5NF. [anne@differentstrokes.co.uk](mailto:anne@differentstrokes.co.uk)

This is a part time post (7.5 hours per week) which can be fulfilled by working from home. Salary £3,198. Closing date for applications 30<sup>th</sup> April 2004. Interviews will be held in June 2004.

**ANNOUNCEMENT!**

Following the advert in Newsletter 23, we are pleased to announce that we have recruited a Regional Coordinator for the North West region. Denise Morrice accepted the post and attended the office for her first day of induction training on 4th March. If you live in the North West and you are willing to help start up a group in your area, Denise is the person to speak to.

Contact Anne at Central Office on 0845 130 7172 and she will pass your information on.

**DON'T JUST BIN THIS NEWSLETTER AFTER YOU HAVE READ IT—RECYCLE IT: TAKE IT TO YOUR DOCTORS SURGERY, HOSPITAL WAITING ROOM, PHYSIO etc**

## APHASIA

The Speakability Helpline provides information to people with aphasia, their families and health-care professionals. Its available Monday to Friday 10:00am to 4:00pm on **0808 808 9572**. Speakability members have formulated this Charter for People with Aphasia:

### Early Days

#### I have the right to:

- Be seen by a Speech and Language Therapist within 2 working days of realising I have difficulty speaking
- A therapy plan discussed with me and my family or carers
- Regular therapy to start as soon as I am ready and for as long as I need
- Information about aphasia in a form I can understand and at the right time
- Information for my family and carers to make sure we all get the help we need

### Living with aphasia

#### I am a person with aphasia. See the person first, not the disability. I have the right to:

- Be seen as a person with a communication difficulty, not a stupid person
- Therapy and support
- Make my own decisions about my life
- Have my views put across accurately by others who speak on my behalf
- People knowing about and understanding aphasia
- Be included in the conversation
- Patience and time when I am communicating
- Access to information and training to help me overcome the barriers I face, so I can lead my life to the full

## Corkscrew clot device has 'potential' - experts

US medical experts expressed cautious support on Monday for a tiny corkscrew-like device that snatches clots blocking critical blood flow to the brain, potentially reversing brain damage in stroke victims.

The experts said the device, called the Merci Retriever, was clearly successful in unblocking blood vessels but could not yet be proven safe in treating stroke.

If the treatment were approved by the agency, which usually follows its panel's advice, it would be the first surgical device used to treat stroke.

The majority of strokes are caused by a blood clot that blocks critical blood supplies to the brain.

Currently, the only Food and Drug Administration FDA-approved therapy to treat strokes is clot-busting drugs, which must be given within three hours and can take two hours to work.

The corkscrew device is snaked through the body via a major artery and then guided into the affected brain artery with a standard catheter. Once the corkscrew snags the clot, it is drawn back out. The entire procedure lasts an average of about two hours, the company told the panel.

Reuters

## PARACHUTING

In Newsletter 23, we ran an advert offering readers the opportunity to jump out of an aeroplane to raise funds for Different Strokes; as a result several people have volunteered—more would be welcome! The pictures here are of Rachel, a volunteer at Central Office, and her friend Colin.

Rachel became involved in Different Strokes because she had a relative who suffered a stroke in his 40s. The relative had another stroke late last year but unfortunately he didn't survive it, so Rachel wore a T-shirt with his picture on the front in his memory.



The jump took place on Saturday 17<sup>th</sup> January at an airfield in Brackley. It was a very cold day, but, as can be seen from the photographs, beautifully clear and sunny. The roads were icy and quite treacherous, particularly on the final leg of the journey, which was a winding, single track road. The conditions didn't put people off however, there were already thirty or more other cars as I parked and prepared to face the biting wind on the airfield.

Colin and Rachel had arrived in plenty of time to go up with the first group, but unfortunately there was a slight delay as the medical form needed a doctor's signature. While this was being sorted out we watched the first plane take off, and

Rachel started showing increasing nervousness about the whole idea, making numerous trips to 'powder her nose' and trying not to show she was worried, as her Mum was even more nervous than she was!

After the first group had returned, Rachel and Colin were helped into their flying suits and harnesses by experienced skydivers who they would be jumping with, in tandem. They took off in a very old fashioned looking aeroplane which then climbed to 10,000 feet. The spectators struggled to keep the plane in view as it became smaller and smaller, and when the parachutists jumped out they were such tiny dots we could hardly see them. The specks slowly grew until we could identify them as human beings, and then the parachutes opened and they continued floating gently down to earth.

Safely back on terra firma, Rachel and Colin were on an exhilaration high, both keen to do another jump as soon as possible. But then came the hard part – collecting in all the sponsorship money they had persuaded people to commit to the cause! They did very well, managing to raise close to fifteen hundred pounds between them, for which we are extremely grateful and which will be put to very good use to help younger stroke survivors.



You too can help us raise funds by making an exhilarating 10,000 feet freefall parachute jump. No experience is required, and if you raise the minimum amount of sponsorship you will get to jump for FREE. For an information pack call 0845 130 7172.

**By Anne Barby**  
**Group Development Manager, Central Office**

### **Virgin olive oil may reduce cholesterol damage**

Just a spoonful of extra virgin olive oil helps the cholesterol go down, results of a small study indicate.

According to the report, adults who consumed 25 millilitres (ml) or nearly 2 tablespoons of virgin olive oil daily for one week showed less oxidation of LDL ("bad") cholesterol and higher levels of antioxidant compounds, particularly phenols, in the blood.

Antioxidants can help prevent oxidative damage, which is caused by free radicals, by-products of the body's normal processes that can damage body tissues. Studies have shown that the oxidation of LDL cholesterol is associated with the hardening of arteries that can lead to heart disease.

**SOURCE: European Journal of Clinical Nutrition**

### **WHY COCOA MAKES YOU FULL OF BEANS**

A bedtime mug of cocoa keeps you looking young and helps fight off cancer and heart disease, research shows.

Scientists have discovered that the drink is packed with healthy antioxidants. Tests have shown that these chemicals may prevent the spread of cancer, slow the ageing process and lower blood cholesterol levels.

Previous studies have touted the health benefits of red wine with a meal and cups of tea during the day - both drinks are known to be high in antioxidants. Researchers at Cornell University in New York found that cocoa or hot chocolate contains twice as much antioxidants, up to three times more than green tea and up to five times more than black tea.

The research is the latest to extol the virtues of the cocoa bean - eating chocolate, which is made from cocoa, is said to reduce stress and release endorphins, chemicals in the brain which act as pain relievers.

### **Women face greater lifetime risk of stroke than men**

Women aged 55 and older face a one-in-five chance of having a stroke, while men of the same age face a one-in-six chance, according to a recent study. Researchers who evaluated data from nearly 5,000 participants found that the lifetime risk of stroke for women at age 55 was 21 percent, for men at age 55 it was 17 percent.

Of the more than 800 people in the study who had strokes, 86 percent were ischemic strokes. An ischemic stroke occurs when the brain does not get enough oxygen-rich blood because a blood clot is blocking an artery leading to the brain. Rapid response to an ischemic stroke can result in little apparent damage, but a stroke left untreated for too long can result in neurological and tissue damage (e.g., permanent loss of speech or paralysis) or death.

According to the American Stroke Association, the study found that the risk for stroke was directly related to high blood pressure at every age for both men and women. People with a systolic blood pressure of 140 mmHg or higher or a diastolic blood pressure of 90 mmHg or higher were found to be at more than twice the risk for stroke than people with normal blood pressure. Researchers also found that for both men and women, the lifetime risk of stroke was lowest when blood pressure was less than 120/80 mmHg at age 55.

## profile

### JO CANDERTON

I was 34 years old, fit as a fiddle and loving life to bits (maybe a bit too much come to think of it now!). My story begins on a hot Thursday night in July 2003 after spending an evening with my mate watching TV and boozing at his house. Friday at work I had the mother of all headaches, my assistant fed me some migraine pills and I drove home feeling dizzy, unable to focus and struggling to change gear in my car. The weekend brought more boozing and merriment with the usual Monday blues following.

Then on Tuesday night at about midnight, my girlfriend wakes me up as I am trying to sit up in bed and cannot do so. She says that my face has dropped and I find that I cannot stand but need to get to the bathroom for a pee, I end up trying to drag myself across the bedroom floor with my right hand. My eyesight had gone as I could not see my dog who was lying on his bed in the corner (panic set in - what was happening to me!!). My girlfriend rang my brother who lives close, he came straight round to my house and rang



for an ambulance. This arrived after about 20 minutes of my brother slapping my face and asking me to count his fingers that he was holding in front of my face. I knew something serious was wrong with me as I could not lift my head or my left arm and I could not stand - I just wanted a pee. The ambulance arrived and the paramedics carried me from our bedroom on the third floor of our house to the back of the waiting ambulance, this whisked me off to the Leicester Royal Infirmary A&E for scans etc. This is where I spent one month on a high dependency ward thinking everything will be ok soon and I will go home to my girlfriend (little did I know??).

After this month I was moved to the Younger Disabled Unit at Leicester General Hospital for rehab (disabled, me? never!!!). I then spent 4 months in the YDU having daily physio and OT (the therapists there were superb, putting up with my moods and cheekiness while trying to get me to walk and function again). After 3 months of wheelchairs and learning to transfer in and out of bed on my own, I decided that it was time to get up on my feet again. I started to walk to and from

the communal bathroom on our ward on my own using just a cane for support, in the dark evenings I would practice taking steps on my own in the reflection of the long window on the ward. The physio soon cleared it for me to walk to the bathroom without my cane, this soon improved to me walking to the kitchen and making my own cups of tea and returning to my bed to continue watching trash day time TV.

It was at my care plan meeting in November when I was given my release date (this was to be the 19th December 2003 - home for Christmas, fantastic!). The next thing was the home inspection by the therapists, and a right handrail being installed on the stairs, bingo I could now sleep upstairs again in my own bedroom (this, I consider to be an important part of my rehab).

I have now been at home for over 6 weeks, I have walked to the corner shop on my own with my cane, I frequently walk the dog with my girlfriend and cane for support, I have been shopping in Leicester town on numerous occasions, I go to the pub regularly with my mates and am currently looking to buy an automatic car to start driving again (BEING AT HOME IS THE BEST FORM OF REHAB—JUST DOING NORMAL THINGS.)

I have all sorts of plans for the future, so please anyone reading this who has just suffered a stroke or is trying to come to terms with it - don't despair it will get better, time is a great healer! Thank you for taking the time to read my story. Good luck all and take it easy

[www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)



Different Strokes has a new Webmaster, Hilda McDonald and a Different Strokes Message Board Master, Peter Allen. Welcome and many thanks to both of them.



**IF YOU HAVE ANY  
REGIONAL NEWS YOU  
WOULD LIKE TO SHARE  
WITH DIFFERENT  
STROKES MEMBERS,  
SEND IT TO  
[info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk)**

**DON'T FORGET TO  
SEND US A  
PICTURE.**

# CLASSES AND CONTACTS

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